STATES OF JERSEY



ASSISTED DYING

Lodged au Greffe on 22nd March 2024 by the Council of Ministers Earliest date for debate: 21st May 2024

STATES GREFFE

2024 P.18

PROPOSITION

THE STATES are asked to decide whether they are of opinion –

- (a) to request the Minister for Health and Social Services to bring forward primary legislation that permits assisted dying in Jersey and that requires the Minister to establish an assisted dying service in accordance with the essential provisions and safeguards outlined in the Appendix accompanying this proposition and to agree that assisted dying will only be lawful where a person meets all of the following eligibility criteria:
 - (i) the person must meet the conditions set out in either paragraphs (b) or (c);
 - (ii) the person must be aged 18 or over at the point at which they make a first formal request for an assisted death;
 - (iii) the person must be ordinarily resident in Jersey;
 - (iv) the person must have a voluntary, clear, settled and informed wish to end their own life; and
 - (v) the person must have capacity to make the decision to end their own life:
- (b) to agree that, in addition to meeting all the eligibility criteria detailed in paragraph (a), the person must have been diagnosed with a terminal physical medical condition which is giving rise to, or is expected to give rise to, unbearable suffering that cannot be alleviated in a manner the person deems to be tolerable and that terminal condition must be reasonably expected to cause the person's death within the timeframe specified in the Appendix, known as 'Route 1 terminal illness';
- (c) to agree that, in addition to meeting all the eligibility criteria detailed in paragraph (a) and if the person does not meet the eligibility criteria detailed in paragraph (b), the person must have an incurable physical medical condition that is giving rise to unbearable suffering that cannot be alleviated in a manner the person deems to be tolerable (which may or may not be a terminal physical condition), known as 'Route 2 unbearable suffering';
- (d) to agree that no person should be under a legal duty to participate directly in the provision of assisted dying and any such person will have a right to refuse direct participation; and
- (e) to agree that there will be a minimum timeframe between the point at which a person makes a first formal request for an assisted death and the administration of the substance that leads to that death.

COUNCIL OF MINISTERS

APPENDIX A

The Assisted Dying Law will include the following provisions and safeguards –

- (i) that, **further to the provisions of paragraph (b)** where a person has a terminal illness, and is eligible under 'Route 1 terminal illness', the specified timeframe will be 6 months, or 12 months in the case of neurodegenerative conditions;
- (ii) that, a person will only be eligible if they have been ordinarily resident in Jersey for a period of at least 12 months before they make their first formal request for an assisted death, the 12-month period according with the Health and Community Services Department's existing Residents and Non-Residents Charging policy;
- (iii) that, **further to the provisions of paragraph (b)** where a person has a terminal physical medication condition, 'Route 1 terminal illness', the minimum timeframe between a person's first formal request for an assisted death and the administration of the assisted dying substance will be 14 days, except for when the person's life expectancy is less than 14 days when there will be no minimum timeframe;
- (iv) that, **further to the provisions of paragraph (c)**, where assisted dying is permitted for people who have an incurable physical condition but where there is no reasonable expectation of death within the specified timeframe 'Route 2 unbearable suffering', the minimum timeframe between a person's first formal request for an assisted death and the administration of the assisted dying substance will be 90 days;
- (v) a person's request for an assisted death must be approved by a Coordinating Doctor, with the Coordinating Doctor only able to approve a request if both the Coordinating Doctor and a second independent doctor have undertaken an assessment of the person and the person's request for an assisted death, and have both determined that the person meets all the criteria set out in law;
- (vi) and that, **further to the provisions of paragraph (c)**, where a person has an incurable physical condition, and is eligible under 'Route 2 unbearable suffering', the Coordinating Doctor's approval must also be subject to confirmation by a Tribunal;
- (vii) that, a person must have capacity throughout the whole assisted dying process (from first formal request to the administration of the assisted dying substance) except for where that person has made a waiver of final confirmation of consent; such a waiver may only be made where a person has a terminal physical medication condition, 'Route 1 terminal illness', and provides that where a person loses capacity after their request for an assisted death has been approved but before the administration of the substance, the substance may still be administered on a date which was previously agreed by the person when they had capacity to do so.

- (viii) a person who has requested an assisted death may withdraw that request at any point up until the point of administration of the assisted dying substance;
- (ix) once a person's request for an assisted death has been approved, that approval will not expire;
- (x) the assisted dying substance that ends a person's life may be
 - i. self-administered by the person; or
 - ii. administered by the Administering Practitioner;
- (xi) the Administering Practitioner must stay with, or nearby, the person whilst the assisted dying substance is administered (regardless of whether the substance is self-administered or administered by the Administering Practitioner) and up until point that the person dies;
- (xii) that, **further to the provisions of paragraph** (**x**), if the person has chosen to self-administer the substance, a family member or loved one may only support them in the process under the guidance of the Administering Practitioner
- (xiii) a person approved for an assisted death will have the option to make a written declaration of 'confirmation of consent to proceed' allowing a healthcare professional to intervene in order to complete the assisted death in the event of medical complications during the process of administration of the assisted dying substance, or post-administration of the substance;
- (xiv) assisted deaths may only take place at a location which is approved as safe and suitable by the Administering Practitioner, to include Jersey General Hospital, and which may include other facilities provided by the Minster for Health and Social Services or another provider, or a private residence;
- (xv) the assisted dying service will only be provided by the Minister for Health and Social Services and will be free at the point of access;
- (xvi) the Jersey Care Commission will register and inspect the Assisted Dying Service:
- (xvii) for the purposes of the Regulation of Care (Jersey) Law 2014, the assisted dying service will not be considered an 'essential service', thereby enabling the Jersey Care Commission to cancel its registration in the event of identified failings, even though it is a service that is only provided by the Minister for Health and Social Services, with any cancellation of registration by the Jersey Care Commission effectively shutting the service down:
- (xviii) the Minister must make arrangements to establish an assisted dying advisory committee to review and authorise all associated guidance, protocols and training for the Jersey Assisted Dying Service, publish an annual report, and arrange a post-death governance review of each assisted

- death, with this committee to include appropriately qualified independent members;
- (xix) all professionals working in the assisted dying service must opt in to doing so and must be placed on the Jersey Assisted Dying Service register, with any such professionals obliged to have undertaken all mandated training, and to meet the minimum qualifications set out in any statutory guidance, in order to opt-in;
- (xx) the Minister for Health and Social Services will make provision for wellbeing support for professionals engaged by the Jersey Assisted Dying Service, and for persons requesting assisted dying and their family and loved ones;
- (xxi) that, **further to the provisions of paragraph (d)**, the right to refuse to participate will be extended to the managers and providers of residential health and care services, to refuse to allow for an assisted death on their premises;
- (xxii) that, the law will provide for an appeals process to the Royal Court regarding decisions about
 - i. a decision of the Coordinating Doctor to accept a determination that the person has been, or has not been, ordinarily resident in Jersey for the required time period stated in paragraph (ii);
 - ii. a determination taken by an Assessing Doctor that
 - a. the person has, or does not, have the decision-making capacity to request an assisted death; and
 - b. the person's wish is, or is not, voluntary, clear, settled and informed; and
 - c. a failure, or perceived failure, to make determinations or to act in accordance with the process set out in law, including through the failing of the service or through maladministration; and
- (xxiii) the persons who may appeal will be
 - i. the person who has requested the assisted death;
 - ii. an agent of the person who has requested the assisted death, namely someone who the person has asked to act on their behalf; or
 - iii. any other person who the Court is satisfied has a special interest in the care and treatment of the person, such as a family member;
- (xxiv) that the assisted dying law will not require health and care professionals to raise the subject of assisted dying with their patients or clients;
- that the assisted dying law will not prohibit health and care professionals from raising the subject of assisted dying with their patients or clients and that guidance will be brought forward setting out how care professionals who conscientiously object should interact with people who request or want information about assisted dying, with the guidance to stipulate that the professional must provide them the contact details of the Jersey Assisted Dying service;



REPORT

Table of Contents

Terms used	12
Section 1: Background	16
Developing the proposals	16
Citizens' Jury and States Assembly 'in-principle' debate	16
Phase 1 & 2 consultation	17
Ethical review	18
Medical indemnity and medical malpractice insurance	21
Personal life insurance	21
Lodging period	21
Section 2: Principles	23
Section 3: Eligibility criteria	27
Health eligibility criteria	27
Route 1 – terminal illness	28
Route 2 – unbearable suffering	30
Ordinarily resident in Jersey	33
Voluntary, clear, settled and informed wish to end their own life	34
Decision-making capacity	34
Application of eligibility criteria	35
Future changes to eligibility criteria	35
Section 4: Jersey Assisted Dying Service	36
Assisted Dying Assurance and Delivery Committee	37
Annual report on assisted dying in Jersey	40
Section 5: Health and care professionals – right to refuse / conscientious	
objection, discussions with patients and registration	42
Right to refuse to directly participate in assisted dying / conscientious obj	
Discussion of assisted dying with patients	
Protections for health and care professionals	
Health and care professionals' involvement in assisted dying	49
Registration as an assisted dying practitioner	49
Support for professionals	
Section 6: Assisted dying process overview	59

	Matters that apply to all steps in the process	60
	Proceeding through the steps / timeframe	60
	Step Transition form	60
	Minimum timeframes	62
	Assisted dying forms and Assisted Dying Person Record	63
	Interpreting, communication support and advocacy	65
	Remote consultations	66
	Involvement and support for family and loved ones	67
	Declaration of Interest form	68
Sec	tion 7: Assisted dying process - request, assessment and approval	70
	Pre-process steps: information and referral to the Jersey Assisted Dying Serv	
	General enquiry	
	Self-referral	
	Professional referral	
	Step 1: First formal request	
	First Formal Request meetings and form	
	Residency	
	Age	
	Step 2: First assessment	
	Presence and cause of suffering	
	Is the suffering bearable?	
	Note: Ethical review – decision-making capacity	92
	Post first assessment determination	92
	Does not meet the criteria	92
	Meets criteria	95
	Step 3: Independent assessment	99
	Post independent assessment	101
	Step 4: Second formal request	102
	Poor service complaints	104
	Safety concern / complaint	104
	Step 5: Approval process	106
	Administrative Review by Coordinating Doctor (approve or decline) and Tri confirmation of approved requests [Route 2 only]	
	Administrative Review by Coordinating Doctor	106

Route 1 (terminal illness) approval	108
Route 2 (unbearable suffering) approval – Tribunal	108
Establishing the Tribunal	111
Expiry of approval	113
Section 8: Appeals	114
Section 9: Assisted dying process – planning and delivery of an assisted	l death.118
Step 6: Assisted Death Care Planning	119
Assisted Death Care Planning	119
Advance Decision to Refuse Treatment	124
Prescribing, preparing and dispensing the assisted dying substance	125
The assisted dying substance	127
Step 7: Assisted death	128
Final Review	129
Methods for administration of an assisted death	130
Complications with administration of the assisted dying substance	132
Step 8: After an assisted death	133
Death Certification	134
Burial / cremation	137
Section 10: Regulation and oversight	138
Service provision and assurance	139
Assisted Dying Review Panel: post-death review	139
Post-death review	140
Panel procedures	143
Membership of Panel	144
Registration and inspection by the Jersey Care Commission	145
Acting on findings arising from inspections or from the Assisted Dying Panel	•
Section 11: Offences	149
Suicide and assisting suicide in Jersey	149
Offences under the assisted dying law	
Section 12: Resource and financial implications, risks and next steps	
Resource and financial implications	
Risks	
Next steps	

Lis	t of a	appendices	170
Ap	pend	lix 1: Policy changes / clarifications	171
Pu	rpos	e of appendix	171
1.	Un	derpinning Principles	172
	a.	Palliative / end of life care services	172
	b.	Assisted dying is not suicide	172
Un	derp	inning Principles: Summary of key changes / clarifications	173
2.	Re	gulation making power	173
4.	Jer	rsey Assisted Dying Service	180
	a.	Jersey Assisted Dying service to be delivered by HCS	180
	b.	Consideration of medical model vs. non-medical model of assisted dyin	ıg 181
	c.	Oversight by HCS Delivery and Assurance board / committee	182
	d.	Publication of annual report on assisted dying	182
Jer	sey A	Assisted Dying Service: Summary of key changes / clarifications	183
5.	He	alth and care professionals	183
	a.	Conscientious objection – right to refuse direct participation	183
	b.	Registration of assisted dying practitioners	184
	c.	Discussion of assisted dying with patients	184
He	alth	and care professionals: Summary of key changes / clarifications:	185
6.	Ass	sisted dying process	185
	a.	Minimum timeframes	186
	b.	Second opinion assessment	186
	c.	Multidisciplinary team to support assessment process	187
	d.	Approval routes	187
	e.	Expiry of approval	188
Ass	sisted	dying process: Summary of key changes / clarifications	189
7.	Ap	peals	189
8.	Pla	nning and delivery of an assisted death	190
	a.	Advance decision for assisted dying	190
	b.	Waiver of final confirmation of consent	191
	c.	Confirmation of consent to proceed	192
	d.	Administering the substance	192
	f.	Recording the cause of death	193
9.	Re	gulation and oversight	194

Regulation and oversight: Summary of key changes / clarifications	195
Appendix 2: List of safeguards and case studies	196
Part 1: list of safeguards	196
Safeguarding objective 1: Eligibility criteria compliance	196
Safeguarding objective 2: Protecting and supporting all islanders	197
Safeguarding objective 3: Practitioners act within the law	200
Safeguarding objective 4: Practitioners are supported and protected win accordance with guidance and law	O
Safeguarding objective 5: High-quality, safe service	204
Part 2: Assisted Dying safeguards – possible scenarios, case studies	206
Person 1	208
Person 2	212
Person 3	216
Person 4	219
Person 5	222
Person 6	225
Person 7	227
Person 8	230
Person 9	234
Person 10	236
Appendix 3: Forms and guidance	239
Appendix 4: Outline of mandatory training	241
Appendix 5: Timeline of activity	245
Children's Rights Impact Assessment	245

Terms used

The following terms have been used in this report and proposition:

- Administering Practitioner the doctor or registered nurse (level 1) who will directly administer the substance used in assisted dying or support the person to self-administer the substance. Works within the Jersey Assisted Dying Service.
- **allied health professional** A qualified person who practises one of a wide range of health-related professions (e.g., Physiotherapists, Speech therapists, Occupational therapists, Social Workers, Pharmacists).
- assessing doctors the Coordinating Doctor and the Independent Assessment
 Doctor (plus the Second Opinion Doctor, where relevant) are collectively
 referred to as "assessing doctors". They will assess the person who has
 requested an assisted death to determine if they meet the statutory criteria. They
 work within the Jersey Assisted Dying Service.
- assisted dying Assisted dying is where a person with a terminal illness, or
 experiencing unbearable physical suffering, chooses to end their life with the
 help of a healthcare professional. They may only do so if they have been
 approved for an assisted death, having been assessed as meeting all the
 eligibility criteria set out in law.
- Assisted Dying Assurance and Delivery Committee The Committee which
 oversees establishment and operations of the Jersey Assisted Dying Service,
 including development of training programmes, plus service and clinical
 protocols and guidance.
- Assisted Dying Person Record a single record detailing all information about
 a person's request for an assisted death and the assessment, approval, planning
 and delivery processes associated with that assisted death, including all required
 forms.
- assisted dying practitioner any professional who is registered with the Jersey
 Assisted Dying Service, having met all registration requirements including
 mandatory training. This includes assessing doctors, Administering
 Practitioners, pharmacy professionals and all members of the multidisciplinary
 team. It does not include the Care Navigator.

- **Assisted Dying Review Panel** Panel established by the Committee to undertake a post-death review of every assisted death, to determine proper adherence to guidance and legislation.
- **assisted dying substance** the combination of drugs/medications, approved by the Assisted Dying Assurance and Delivery Committee, used for the purpose of causing the person's assisted death.
- Care Navigator non-clinical staff who will support the person requesting an
 assisted death and support the Coordinating Doctor to coordinate process. Initial
 point of contact for information and enquiries into the Jersey Assisted Dying
 Service. They must have done the mandatory assisted dying training, but they
 do not need to be registered with the Assisted Dying Service because they are
 not clinical staff.
- Coordinating Doctor the doctor who: undertakes the first assessment of the person who has requested an assisted death, coordinates the whole assessment process; makes the decision to approve the request (prior to confirmation by Tribunal for 'Route 2' requests) or decline the request. Works within the Jersey Assisted Dying Service.
- **conscientious objection** Conscientious objection is when a healthcare practitioner chooses not to participate in a legally and clinically appropriate treatment or procedure because it conflicts with their personal beliefs and values. Healthcare professionals will have the right to conscientiously object to assisted dying under the assisted dying law.
- **decision-making capacity** refers to a person's ability to make day-to-day decisions about legal, medical / health care, financial and personal matters. In this context it specifically refers to the person's capacity to make the decision to request an assisted death.
- **doctor** -the term doctor has been used in this report for ease of understanding. It refers to a medical practitioner who is registered with the UK's General Medical Council (GMC) and with the Jersey Care Commission. This may include a general practitioner (GP), middle grade doctor or a consultant.
- **health and care professional** any doctor, registered nurse, allied health professional or any person employed to provide care to a person in Jersey, including residential and domiciliary care.
- Health and Community Services Department (HCS) The Government of
 Jersey's Health and Community Services Department, overseen by the Minister
 for Health and Social Services. Responsibilities of the Department include the
 provision of a wide array of hospital services, social care and support in the
 community, as well as the monitoring and improvement of service quality and
 the education and development of health and care professionals.

- **Independent Assessment Doctor** the doctor who undertakes the second, independent assessment of the person who has requested an assisted death. Works within the Jersey Assisted Dying Service.
- involved professional is an assisted dying practitioner who is involved in the
 assisted dying process for a specific individual. This may include the assessing
 doctors, the Administering Practitioner, the pharmacy professional and any
 members MDT who that specific individual. It does not include the Care
 Navigator.
- Jersey Assisted Dying Service provides access to assisted dying in Jersey.
 The Jersey Assisted Dying Service will be managed and delivered by Health
 and Community Services Department (HCS). [See section 4 Jersey Assisted
 Dying Service]
- **Jersey Care Commission (JCC)** Regulates and inspects health and care services for both adults and children in Jersey. The JCC also registers and regulates healthcare professionals in Jersey. The JCC will regulate the Jersey Assisted Dying Service [see section 10 Regulation and oversight].
- Multidisciplinary team (MDT) member an MDT will be formed to support
 the assessment process for each person who requests an assisted death. In
 addition to the assessing doctors, the MDT may include a registered nurse (level
 1), social worker and any relevant allied health professionals (e.g., a speech &
 language therapist)
- other attending practitioners and carers the term used to describe service providers who may be involved in care or treatment of the person who has requested an assisted death (for example, a domiciliary care provider, a community or hospital nurse, a GP) but who are not directly involved in the assisted dying request, assessment, approval or administration process (except for, where they are asked to undertake a supporting assessment, or provide information or advice to support an assessment or determination [and do not conscientiously object to doing so].)
- **Pharmacy Professional** pharmacist or pharmacy technician who has registered with the Jersey Assisted Dying Service. Will prepare and dispense the substance used in assisted dying, will work within the Hospital Pharmacy.
- **physical medical condition** a broad term that includes all diseases, lesions, injuries, and disorders, but does not include mental illnesses.
- **practitioner-administration** / **practitioner-administered** denotes when a doctor or registered nurse administers / has administered the assisted dying substance which ends the person's life. This would usually be the administration of the assisted dying substance intravenously [see section 9 Assisted dying process planning and delivery of an assisted death. Step 7: Assisted death].

- **registered nurse** the term registered nurse has been used in this report for ease of understanding. It refers to a registered nurse (level 1) who is registered with the UK's Nursing and Midwifery Council (NMC) and with the Jersey Care Commission.
- **Second Opinion Doctor** the doctor who undertakes an additional first or second assessment, if requested by the person. [see paragraph 305] Works within the Jersey Assisted Dying Service.
- **self-administer / self-administration** denotes when a person takes / has taken the assisted dying substance themselves to end their life. This would usually be the ingestion of the assisted dying substance orally.
- **the person** refers to the person who has requested an assisted death. They are not referred to a patient or a client because, in some cases, they will be individuals who are not receiving treatment or care from a service provider.

Note: Terminology

This report uses language that has been updated since the P95/2021 debate:

- a. 'self-administer' is used to denote when a person takes the assisted dying substance themselves to end their life, and
- b. 'practitioner administered' is used to denote when a doctor or registered nurse administers the assisted dying substance to the person

The 'in principle' debate (P95/2021), used the terms 'physician assisted suicide' (in place of 'self-administer') and 'voluntary euthanasia' (in place of 'practitioner administered'). The terminology was updated for two reasons:

- i. to improve clarity: 'self-administer' clearly indicates the person takes the medication themselves whereas 'physician assisted suicide' lacks clarity
- ii. to align the language in an international context: the updated terms are used in most jurisdictions where assisted dying is permitted, including most English-speaking countries (New Zealand, Australia and Canada).

This report sets out detailed proposals for establishing an assisted dying service in Jersey, including all processes and safeguards.

Section 1: Background

This section of the report provides background to the report, outlining previous decisions made by the States Assembly and explains how the proposals were developed. It also details activity during the lodging period.

Developing the proposals

 The proposals outlined in this report have been developed following several phases of consultation with the public and with professional stakeholder organisations.

Citizens' Jury and States Assembly 'in-principle' debate

- 2. In November 2021 the States Assembly ('the Assembly") agreed, in principle, that assisted dying should be permitted in Jersey (P95/2021)¹ but that, prior to the preparation of the law drafting instructions, detailed proposals should be brought back to the Assembly for debate.
- 3. P95/2021 was informed by the key recommendations of the Jersey Citizens' Jury on Assisted Dying which took place between March and May 2021, with the final Citizen's Jury report being published on 16 September 2021.²
- 4. The Jersey Citizens' Jury on Assisted Dying was commissioned by the previous Minister for Health and Community Services, Deputy Richard Renouf, following community interest in the introduction of assisted dying in 2018.³
- 5. A citizens' jury is a form of deliberative democracy, where a small group of people, representative of wider demographics of a given area, come together to carefully consider a complex issue. The Jersey Citizens' Jury on Assisted Dying consisted of 23 Jersey residents who were broadly representative of the Island's population in terms of age, gender, location, socio-economic status, place of birth and attitude towards assisted dying. The jury members came together over 10 online sessions to examine evidence, hear from expert witnesses and consider the central question "Should assisted dying be permitted in Jersey and if so, under what circumstances?".

¹ https://statesassembly.gov.je/assemblypropositions/2021/p.95-2021.pdf

² Final Report from Jersey Assisted Dying Citizens' Jury (gov.je)

³ Citizens' Jury on assisted dying in Jersey (gov.je)

6. At the end of the jury process, 78% of jury members agreed that assisted dying should be permitted in Jersey.⁴

Note: Citizen's deliberation processes

The use of citizen's deliberation processes, such as a jury, is relatively new to Jersey and, as such, some Assembly members raised questions about the process during the P95/2021 debate. The Public Accounts Committee subsequently reviewed the use and effectiveness of such processes and concluded that the Jersey Citizens' Jury on Assisted Dying should be utilised as the model of best practice when establishing future deliberative bodies.⁵

7. During the P95/2021 debate, the Assembly noted the need for further consultation with both the public and professional stakeholders, in order to inform the development of the detailed proposals outlined in this report. That was undertaken in two phases.

Phase 1 & 2 consultation

- 8. During March and April 2022, Islanders were asked to take part in the Phase 1 of public engagement on assisted dying proposals. Following the 'in principle' decision made by the Assembly, Islanders were invited to share their comments, thoughts and questions on assisted dying in Jersey. Feedback from the public was collected online via email, social media and sli.do, and in person at a series of engagement events at various parish halls and the town library. Views were collected and published as key themes and questions in the Phase 1 public engagement summary report.⁶
- 9. Phase 2 of the public consultation focussed on detailed proposals for assisted dying in Jersey and took place over a 12-week period between October 2022 and January 2023.⁷ Approximately 1,300 people and organisations responded to this second phase of consultation. The consultation feedback report was published on 28 April 2023.⁸

Note: changes to timeframe for consultation and proposal development

Following the June 2022 elections, the new Minister for Health and Social Services ("the Minister") determined that the P95/2021 timetable as amended – which stated

⁴ Detailed reports relating to the establishment of the Jury and the Jury's final recommendations can be found at www.gov.je/assisteddying

⁵ p.a.c.1 2022 - use and operation of citizens' panels, assemblies and juries in jersey.pdf (gov.je)

⁶ Public engagement summary report on assisted dying in Jersey (gov.je)

Assisted dying in Jersey consultation (gov.je)

⁸ Assisted Dying in Jersey Phase 2 Consultation Feedback Report (gov.je)

that proposals should be brought to the Assembly by October 2022 – should be extended to allow more time for the public, professional stakeholders and States Members to consider such detailed and ethically complex proposals.⁹

In addition, the proposals were further delayed for the following reasons:

- Phase 2 public consultation launch was delayed by one month due to death
 of Her Royal Majesty, Queen Elizabeth II and subsequent national mourning
 period.
- **Publication of the Phase 2 consultation feedback** was delayed by 6-weeks due to high response levels. Additional time was required to analyse the responses many of which were very detailed.
- Commissioning of ethical review in April 2023 Council of Ministers agreed an independent ethical review should be commissioned due to the lack of consultation feedback consensus. This ethical review, which was an additional, unscheduled activity could not commence until August 2023 due to ethicists' teaching commitments. The Ethical Review was published on 7 November 2023.
- Decision to delay lodging of Report and Proposition until Q1 2024 in consultation with Health and Social Services Scrutiny Panel, the Minister for Health and Social Services agreed that lodging of the report and proposition should be delayed avoiding the Christmas period. Additionally, the Chief Minister determined that a Ministerial Working Group should be established to confirm detailed proposals, prior to sign-off by Council of Ministers. This required additional time for the working group to meet and approve the proposals. Following the vote of no confidence in the previous Chief Minister in January 2024, a new Council of Ministers was formed and these proposals were lodged by the Council of Ministers on 22 March 2024.

Ethical review¹⁰

- 10. Having considered the phase 1 and phase 2 consultation feedback, which was extensive and demonstrated a wide range of views towards the proposals, the previous Council of Ministers endorsed a recommendation by the former Minister for Health and Social Services to commission an external ethical review of the proposals. This was done with a view to ensuring that States Members would be sighted on the range of complex ethical and moral considerations associated with these proposals.
- 11. The ethical review was undertaken by a team of three experts of medical ethics and law, who hold a range of views on assisted dying, as set out in the introduction to that review:

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⁹ P.95-2021 Amd.pdf (gov.je)

¹⁰ Assisted Dying in Jersey Ethical Review Report (gov.je)

- Professor Richard Huxtable is in favour of adopting a "middle ground" (or compromise) position on assisted dying, which seeks to accommodate arguments for and against allowing assisted dying;
- Professor Trudo Lemmens has become increasingly concerned about how assisted dying regimes develop over time. He is opposed to legalising the practice outside a clearly delineated end-of-life context and is concerned about the overall ability to monitor the practice;
- Dr Alexandra Mullock is broadly in favour of assisted dying as a compassionate response within a carefully regulated scheme that safeguards individuals who might be regarded as vulnerable if assisted dying is permitted.
- 12. The ethical review summarises ethical arguments on key aspects of assisted dying and maps these ethical considerations across the Jersey-specific proposals.
- 13. The review authors worked on the basis that assisted dying would be permitted in Jersey (as per the States Assembly P95/2021 "in principle" decision). As such, the authors did not engage with the general question of whether (or not) it would be appropriate to legalise assisted dying; rather, they focused on the proposals set out in Phase 2 consultation. They were specifically asked to address 16 questions focused on the ethical considerations related to proposed eligibility criteria, assessment, approval and delivery process in Jersey, and associated key safeguards. These questions are detailed Chapter 1 of the Assisted Dying in Jersey Ethical Review report.

Appendix 1 sets out findings of the ethical review in relation to the proposed eligibility criteria.

<u>Professional Leads working group, UK professional bodies and expertise in other jurisdictions</u>

- 14. A Government of Jersey Professional Leads working group was established in February 2022 to advise on matters relating to assisted dying service development and delivery. That group included the Medical Director; Chief Nurse; Chief Pharmacist; Chief Allied Health Professional; Director of Mental Health & Adult Social Care; Associate Medical Director for Prevention, Primary and Intermediate Care; Accident and Emergency Consultant GMC lead contact, plus the Chief Inspector of the Jersey Care Commission as an observer. It is supported by policy representatives from SPPP (Strategic Policy, Planning and Performance).
- 15. The Phase 2 consultation and a draft of this report and proposition were reviewed by the Jersey Care Commission, who have confirmed that they agree

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¹¹ Professional leads working group Terms of Reference can be found at https://www.gov.je/Caring/AssistedDying/Pages/AssistedDying.aspx

the proposed arrangements for the regulation and inspection of the Jersey Assisted Dying Service.

- Individual and collective sessions have taken place with General Medical Council (GMC); Nursing and Midwifery Council (NMC); Health and Care Professions Council (HCPC) and General Pharmaceutical Council (GPhC). Topics for consideration have included: conscientious objection; how the introduction of legislation may impact on professional registration requirements; guidance and training for professionals and oversight of registered professionals. The GMC and NMC provided formal feedback to the Phase 2 consultation and a draft of this report and proposition. HCPC were provided with copies of the Phase 2 consultation and a draft of this report and proposition. The GPhC was provided with copies of the Phase 2 consultation and a draft of this report and proposition but did not provide formal feedback.
- 17. Discussion of the proposals has taken place with the British Medical Association (BMA), who provided formal comment in a letter to the Minister in February 2024. ¹²In addition, preliminary conversations with the Academy of Medical Royal Colleges and the Royal College of Nursing have been held.
- 18. The policy proposals set out in this report are based on extensive research of assisted dying legislation and practice in jurisdictions where assisted dying is permitted. This is in addition to in-person / online discussions with professionals in other jurisdictions who have direct expertise and practical experience of assisted dying, including:
 - The Netherlands:
 - o Former Chairman of the Dutch Euthanasia Review Committee
 - Bioethics specialist and former committee member of the Dutch Euthanasia Review Committee
 - Canada:
 - Palliative care consultant and assisted dying practitioner, former President, Canadian Medical Association
 - Specialist palliative care physician, who does not practise assisted dying
 - Australia:

¹² bma-letter-to-deputy-tom-binet-feb-2024.pdf

^{*} during EPSO [European Partnership for Supervisory Organisations] Assisted Dying/ End of Life supervision working group

- Consultant anaesthetist and assisted dying practitioner
- o Palliative Care Physician and assisted dying practitioner
- Chair, Voluntary Assisted Dying Implementation Taskforce, South Australia*
- New Zealand:
 - Assisted Dying Registrar for New Zealand*

Note: Engagement to date with insurance providers

Medical indemnity and medical malpractice insurance

Discussions with relevant insurance brokers indicates that insurance cover for health professionals takes account of the legislation in the jurisdiction in which the health professional is working. Therefore, if assisted dying becomes legal in Jersey, medical indemnity insurance could extend to assisted dying professionals operating within that legislative framework.

Personal life insurance

The Association of British Insurers has indicated that, where an assisted death has taken place legally and a person benefiting from an insurance policy is not directly involved in that death, any claim on a life insurance policy would likely be payable, assuming all other terms and conditions of the policy had been satisfied.

During these discussions the representative bodies indicated that they would reengage in further discussions once the current proposals have been confirmed by the States Assembly (i.e., after the debate on this proposition) when there is more certainty as to the legislative provisions that will be brought forward.

Lodging period

19. The standard minimum lodging period for a proposition brought forward by the Council of Ministers is 6 weeks. Given the complexity and detail of these proposals, the lodging period for this proposition has been increased to 9 weeks. The use of an extended lodging period is in-line with other complex and extensive proposals considered by the States Assembly, such as the Government Plan.

States Members

- 20. During the lodging period Health Policy officers will provide for Assembly Members:
 - 3 x 2-hour briefing sessions on the full proposals

• scheduled weekly 'drop in' sessions, enabling Members to discuss and ask questions on the detail of the proposals on a 1-to-1 basis

Public and professional briefings

- 21. During the lodging period, a series of public briefings on the proposals will take place:
 - 2 x public briefing sessions
 - 2 x dedicated health and care professional briefing sessions

Targeted engagement

22. In addition, during the lodging period targeted consultation work will be undertaken with disabled Islanders, as recommended by the ethical review. These consultation sessions will focus on 'Route 2' – unbearable suffering as a proposed eligibility criteria. Feeback from these consultation sessions will be lodged as an addendum to the report and proposition by the Council of Ministers 2 weeks before the scheduled date for debate.

Section 2: Principles

- 23. Assisted dying is where a person with a terminal illness, or experiencing unbearable physical suffering, chooses to end their life with the help of a medical professional. Assisted dying will only be permitted in certain limited circumstances that will be set out in law.
- 24. The assisted dying proposals set out in this report are underpinned by the following principles:
 - i. <u>Autonomy and choice</u> a person is entitled to genuine choice when determining their end-of-life care and treatment. Their autonomy to make the decisions that are right for them should be respected. It is already the case that some people refuse care and treatment at end of life, whether on religious grounds or to avoid what they deem to be a protracted dying process, whilst others make advanced directives setting out their refusal of treatments or interventions such as resuscitation.

Some people will choose an assisted death because they want to exercise a degree of control over the end of their life and any associated suffering. This is a legitimate choice.

ii. Assisted dying is a voluntary, settled and informed wish – a person requesting an assisted death should only do so if they wish to end their life, and that wish must be free from coercion. Nobody should feel pressurised by family, friends or by wider society to choose, or not to choose, an assisted death.

In making their decision, people will consider a lot of different factors, one of which may be the distress felt by loved ones if the last weeks of their life involve suffering. This is a legitimate consideration, one with which people currently grapple when considering their care options.

The law, and the assisted dying process, must provide safeguards to help ensure that a person's wish is free from coercion or pressure but, in doing so, it must be recognised that a voluntary wish, that is freely made, may be influenced by our love and concern for others. [See paragraph 56 for detail on settled and informed nature of request]

iii. Palliative and end of life care services — assisted dying does not replace palliative care and end-of-life care services. A person approaching the end of their life or living with serious illness should be provided the care and treatment they need to maximise their quality of life and minimise any suffering or distress. Assisted dying is an additional choice that some people may make because they want more control over the manner and timing of their death. In jurisdictions where assisted dying is permitted, including Canada, Australia and

New Zealand, the majority of people requesting an assisted death are also receiving palliative care (82.8%, 82.2% and 76.2% respectively). 131415

Any person seeking an assisted death should be making a real choice. They should not choose an assisted death on the basis that they cannot access – or believe they cannot access – high quality end-of-life or palliative care services.

Hence, it is envisaged that, should these proposals be accepted, the draft law to be presented to the Assembly will ask Members to agree, in principle, that legislation permitting assisted dying should not be brought into force until the Assembly is satisfied that decision taken in the 2023 Government Plan to provide for additional investment in end of life and palliative care is supporting improvements in quality and availability of those services.

This will require information and evidence of the improvements that are in train, to be presented to the Assembly as part of any future debate on an appointed day act to bring the anticipated assisted dying law into force.

In addition, consideration will be given to placing a statutory duty on the Minister for Health and Social Services to provide palliative care and end of life care as part of proposed Adult Safeguarding Law that is currently in development.

Note: Enhancing Jersey's current Palliative and End of Life Care offering

A Palliative and End of Life Care Strategy for Adults in Jersey was published on 14 November 2023. 16 The overarching aim of this strategy is to enhance the quality of palliative and end of life care services in Jersey, regardless of the person's underlying illness or the care setting. The Island-wide strategy is a collaborative effort between Jersey Hospice Care, Jersey End of Life Care Partnership Group, Health and Community Services, and Public Health. It sets out a 3-year vision to ensuring positive access to high quality care for all people and their families when approaching the end of their life.

The 2023 Government plan has committed to between 2 and 3 million pounds additional annual spend on end of life and domiciliary care provision in Jersey between 2023-2026.¹⁷

Key metrics for success of the strategy in the longer term, will include:

- 100% of health and care professionals working across community, hospital and Hospice will have access to educational sessions around palliative care and end of life care on a monthly basis.
- 100% of patients at home have access to 24 / 7 model of palliative care

¹³ Second Annual Report on Medical Assistance in Dying in Canada 2020 - Canada.ca

¹⁴ Voluntary Assisted Dying Review Board report of operations: January to June 2021 (safercare.vic.gov.au)

¹⁵ Assisted Dying Service – Ngā Ratonga Mate Whakaahuru. Registrar (assisted dying) Annual Report to the Minister of Health

¹⁶ A Palliative and End of Life Care Strategy For Adults in Jersey (gov.je)

¹⁷ Government Plan 2023 to 2026 Annex.pdf

- Services will be set up to enable more patients to achieve their wishes with these set out in their advance care plans where at least:
 - o 75% of patients will achieve their preferred place of care.
 - o 75% of patients will achieve their preferred place of death.
- 100% of carers will be supported throughout the palliative care experience of their loved one.

These metrics may not have been fully realised at the point of consideration of the draft assisted dying law by the States Assembly.

- iv. <u>Health professionals</u> the law will provide that no health or care professional can be compelled to directly participate in the assessment, approval or delivery of an assisted death. The right of any person to conscientiously object and decline to particate does not, however, extend to obstructing the choice of a person who wishes to have an assisted death. This means that a care professional, who is providing care to a patient who wishes to seek information about assisting dying, will be required signpost a patient to the assisted dying service.
 - Professionals who do choose to participate in the assisted dying process must have access to support services that help them process and reflect on the emotions associated with assisting someone to die.
- v. <u>Assisted dying is not suicide</u>— whilst both assisted dying and suicide result in intentionally ending one's own life, when a person dies by suicide it is a lonely act, carried out outside of a legal framework, and is accompanied by mental and physical pain and fear. Suicide invariably leaves behind a legacy of stigma and irresolvable grief for loved ones. Assisted dying can be the exact opposite, it provides a safe, calm and considered environment in which a person most often with the support of their loved ones can end their life and associated suffering. The law will set out that assisted dying is not suicide.

Note: Consultation feedback and suicide

Phase 2 consultation received feedback that was both supportive of the statement 'assisted dying is not suicide' (for example, a submission from the Attorney General of South Australia) and feedback that was opposed to this statement (for example, submissions from campaigning organisations, including the Christian Institute).

During Phase 1 some feedback expressed concern that the introduction of assisted dying would lead to a rise in the rate of suicides, whilst others suggested the reverse; that the introduction of assisted dying would provide an alternative for people currently considering suicide because of the suffering associated with severe health conditions.

Several studies have been undertaken to try to understand if there is a link between assisted dying and increased rates of suicide, but these studies reach different

findings.¹⁸ ¹⁹ ²⁰²¹ Recent data shows that overall suicide rates have increased in recent years in some jurisdictions since the introduction of assisted dying (for example, the US^{22} and the Netherlands²³) but declined in others (for example, Belgium²⁴ and Canada²⁵).

A 2022 UK Office of National Statistics bulletin shows that there are elevated rates of suicide in patients with severe health conditions. For example, for people diagnosed with chronic obstructive pulmonary disease (COPD) and chronic heart conditions, the suicide rate is two times higher than for the rest of the population with similar socio-economic characteristics.²⁶

vi. Family and friends – family members and close personal contacts will be supported throughout the process, including being supported to openly discuss their loved one's preferences and choices. Ultimately, however, the choice of an assisted death can only be made by the person requesting it. The family cannot request an assisted death, nor can they block the person's wishes.

¹⁸ How does legalization of physician assisted suicide affect rates of suicide? - St Mary's University Open Research Archive (stmarys.ac.uk)

¹⁹ Perma | jemh.ca

²⁰ The effect of assisted dying on suicidality: a synthetic control analysis of population suicide rates in Belgium | SpringerLink

²¹ Investigating the relationship between euthanasia and/or assisted suicide and rates of non-assisted suicide: systematic review - PMC (nih.gov)

²² Suicide mortality rate (per 100,000 population) - United States | Data (worldbank.org)

²³ Suicide mortality rate (per 100,000 population) - Netherlands | Data (worldbank.org)

²⁴ Suicide mortality rate (per 100,000 population) - Belgium | Data (worldbank.org)

²⁵ Suicide mortality rate (per 100,000 population) - Canada | Data (worldbank.org)

²⁶ Suicides among people diagnosed with severe health conditions, England - Office for National Statistics

Section 3: Eligibility criteria

This section of the report sets out the proposed eligibility criteria for assisted dying. These criteria broadly accord with those agreed 'in principle' by P95/2021, subject to a number of clarifications and use of revised terminology to ensure consistency and help aid understanding and accuracy.

This section focuses on describing the criteria – additional information about the policy rationale underpinning the criteria and the associated consultation feedback is set out separately in appendix 1 – Policy changes/clarifications.

Summary of eligibility criteria

Assisted dying will only be lawful where a person meets all of the following eligibility criteria:

a. the person must either:

Route 1 (terminal illness)

have been diagnosed with a terminal physical medical condition which is giving rise to, or is expected to give rise to, unbearable suffering that cannot be alleviated in a manner the person deems to be tolerable and that terminal condition must be reasonably expected to cause the person's death within 6 months or 12 months in the case of neurodegenerative conditions;

OR

Route 2 (unbearable suffering)

have an incurable physical medical condition that is giving rise to unbearable suffering that cannot be alleviated in a manner the person deems to be tolerable (which may or may not be a terminal physical condition);

- b. the person must be aged 18 or over at the point at which they make a first formal request for an assisted death;
- c. the person must be ordinarily resident in Jersey;
- d. the person must have a voluntary, clear, settled and informed wish to end their own life;

and

e. the person must have capacity to make the decision to end their own life.

Health eligibility criteria

- 25. It is proposed that a person may be eligible for assisted dying on medical grounds in one of two ways:
 - a. 'Route 1 terminal illness', or
 - b. 'Route 2 unbearable suffering'

Every person who requests an assisted death, whether under Route 1 or Route 2, will be assessed for eligibility by a minimum of two doctors, but the approval process for the two routes will differ. [See section 7 – Assisted dying process – request, assessment and approval. Step 5: Approval process]

Route 1 – terminal illness

- 26. For a person to be eligible under 'Route 1 terminal illness', they must have been diagnosed with a medical condition that meets all four qualifications below:
 - 1. a terminal physical medical condition
 - 2. that is giving rise to, or is expected to give rise to unbearable suffering
 - 3. that cannot be alleviated in a manner the person deems to be tolerable, and
 - 4. that is reasonably expected to cause the person's death within the timeframe specified.

Qualification 1: a terminal physical medical condition

- 27. The term 'terminal physical medical condition' is used in place of 'illness' (as per P95/2021) for the purposes of clarity. A 'terminal physical medical condition' includes all physical diseases, lesions, injuries, and disorders to which there is no current cure and which is expected to result in the death of the person.
- 28. The criteria only apply to physical conditions and <u>do not include mental or psychiatric illness or disorders</u>. Neurodegenerative conditions such as Alzheimer's disease, would fall within the physical conditions criteria. However, a person with Alzheimer's would only be eligible for assisted dying if they retain their decision-making capacity (see paragraph 57 decision-making capacity).²⁷
- 29. Examples of mental and psychiatric illness or disorders which do not fall within the criteria include anxiety disorders (for example, obsessive-compulsive disorders and phobias); depression, bipolar disorder and other mood disorders;

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²⁷ Metal illness, as recognised by international disease classification resources such as the Statistical Manual of Mental Disorders, Fifth Edition <u>Psychiatry Online | DSM Library</u> or Mental, behavioural or neurodevelopmental disorders states in the ICD-11 <u>International Classification of Diseases (ICD)</u> (who.int)

eating disorders; personality disorders; post-traumatic stress disorder; psychotic disorders, including schizophrenia.

Qualification 2: that is giving rise to, or is expected to give rise to unbearable suffering

30. Under 'Route 1 – terminal illness', the person must either be experiencing current unbearable suffering as a result of their physical medical condition OR the person must have an expectation that their incurable physical medical condition will, before their death, give rise to suffering which they are likely to find unbearable.

Qualification 3: cannot be alleviated in a manner the person deems to be tolerable

- 31. There may be treatment options available that alleviate suffering to a degree, or result in longer life expectancy, but the person may consider those treatment options too invasive, painful or debilitating to be tolerable for example, a patient may decline chemotherapy because of the associated side-effects. A person always has the right to choose to decline treatment.
- 32. Consideration was given as to whether to include a test of the 'reasonableness' of a person's tolerance of care or treatment that may alleviate suffering (i.e. the reasonableness of the person's right to refuse treatment). Consideration was given to the following factors as potential reasons for refusing certain care or treatment:
 - a. history of care and treatment provided (i.e., has the person already received care and treatment; to what degree has it been effective; to what degree has the person found it be ineffective, invasive etc)
 - b. history of refusal to engage in care and treatment (the person may have an established history of refusal of care or treatment which derives from their personal view or entrenched mistrust)
 - c. the religious, spiritual or personal beliefs and views of the person
 - d. the potential for any coercion in the decision to refuse treatment
 - e. known potential outcomes associated with care and treatment options (for example, is it likely that the care and treatment options will provide only marginal relief)
 - f. the degree of physical and mental suffering experienced by the person and the potential for the care and treatments to reduce that suffering
- 33. In consultation with UK professional regulatory bodies, legitimate questions were raised around the potential challenges for assessing doctors in determining the reasonableness of a person's right to refuse treatment. It was noted that a 'reasonableness' test could have the consequence of interfering with the longestablished principle of a person's right to refuse treatment on any grounds.

Therefore, a test of reasonableness has not been included. However, (as noted in paragraph 285 – Informed wish for assisted dying) during the assessment process the assessing doctor has a duty to ensure the patient is fully informed about all care and treatment options available to the person, before they can be assessed as eligible.

Qualification 4: that is reasonably expected to cause the person's death within the timeframe specified.

- As per paragraph i of Appendix A of the proposition, where a person has a terminal illness and is eligible under 'Route 1 terminal illness', the specified timeframe for Qualification 4, where the terminal illness is reasonably expected to cause the person's death will be 6 months or 12 months in the case of neurodegenerative conditions.
- 35. Whilst it is acknowledged that doctors cannot be exact when predicting an individual's life expectancy, reasonable predictions can be made, based on statistical data available for most diseases. As with all medical prognoses, different people will have different disease progression trajectories. The law will therefore provide that the assessing doctors may make an assessment of life expectancy which they determine is reasonable based on their medical knowledge and their examination / assessment of each individual person.
- 36. The 6-month timeframe for the majority of terminal illnesses accords with the P95/2021 'in principle' decision, as well as legislation in a number of other jurisdictions, including New Zealand, US states (such as Oregon, California and Vermont) and Australian States (including Victoria, Western Australia and New South Wales).
- 37. This proposition unlike P95/2021 also provides a 12-month specified timeframe for people who have a terminal neurodegenerative disease which, due to the nature of the disease, is likely to see a significant deterioration in quality of life and associated potential for unbearable suffering significantly before the person reaches the point of having six months life expectancy.
- 38. The inclusion of a 12-month life expectancy for neurodegenerative diseases mirrors provision in Australia (New South Wales, South Australia, Tasmania, Victoria and Western Australia). Neurodegenerative diseases include Motor Neuron Diseases (MNDs) and Parkinson's Disease.

Route 2 – unbearable suffering

- 39. In P95/2021, the Assembly decided, in principle, that assisted dying should be permitted in relation to non-terminal illness, for example where a person has life changing injuries because of a motor vehicle accident and those injuries cause unbearable suffering but do not necessarily shorten their life expectancy. [See also below Note: Terminal diagnosis Route 1 or Route 2.]
- 40. This mirrors the assisted dying laws in Canada, Belgium, the Netherlands, Spain, Switzerland and Austria but is different to the laws in Oregon and other

- US states, Australia and New Zealand which only permit assisted dying where a person has a terminal illness.
- 41. For a person to be eligible under 'Route 2 unbearable suffering', their medical condition must meet all three qualifications below. They must have been diagnosed with:
 - 1. an incurable physical medical condition
 - 2. that is giving rise to unbearable suffering
 - 3. that cannot be alleviated in a manner the person deems to be tolerable.

Qualification 1: an incurable physical medical condition

42. As with 'Route 1 – terminal illness', only those with a physical medical condition, not a mental or psychiatric condition, may be eligible. [see paragraphs 27-29]

Qualification 2: that is giving rise to unbearable suffering

- 43. Unlike 'Route 1 terminal illness', a person will only be eligible if they are currently experiencing unbearable suffering (i.e., not an expectation of future unbearable suffering).
- 44. The assessment process acknowledges that the tolerability of suffering is subjective and can fluctuate. Different people experience suffering in different ways. It is only the person affected who can determine if they can bear their suffering. During the assessment process, the assessing doctor must work with the person to support them to articulate the nature of their suffering.
- 45. Suffering is defined to include both physical and mental suffering as a direct result of their eligible physical medical condition and may also include suffering caused by the treatment provided for the physical medical condition.

[see paragraphs 248-268– for detail on the nature and assessment of suffering]

Qualification 3: cannot be alleviated in a manner the person deems to be tolerable

46. As with 'Route 1 – terminal illness', a person has the right to refuse medical treatment that is not acceptable to them. However, as part of the assessment process, the assessing doctors must work to help ensure that the person understands what options and treatments are available to them that may potentially alleviate their suffering, including identifying what options they have tried previously (and the extent to which these have worked) and what options they may be willing to try. [see paragraphs 248-268 and, see paragraphs 31-33 above, regarding consideration of a 'reasonableness' test.]

47. For those with a terminal diagnosis but with a life expectancy that is longer than the specified timeframes (i.e. 6 or 12 months), they may be assessed as eligible under 'Route 2 – unbearable suffering', if they are experiencing current suffering.

Note: Terminal diagnosis - Route 1 or Route 2

A person with a terminal illness may be eligible for an assisted death under Route 1 or Route 2, if they are currently experiencing suffering (as distinct from anticipation of future suffering).

Where the anticipated life expectancy of the person falls within the specific timeframes (i.e., no more than 6 months or 12 months if neurodegenerative), the person's request would be assessed via Route 1 processes, not Route 2. (This forgoes the requirement specified in Route 2, for any approval to be confirmed by a Tribunal as the person has limited life expectancy).

Where the anticipated life expectancy of the person is more than the specified time period, the person's request could be assessed and approved Route 2.

In the event the Assembly adopt Route 1 but not Route 2, people with a terminal illness and a life expectancy of more than the specified time frame would not be eligible to request an assisted death until they fall within the specified time frame.

Must be aged 18 or over

- 48. It is proposed that assisted dying should only be permitted for adults i.e., a person must be aged 18 years or over at the time they make their first formal request for an assisted death. A first formal request is Step 1 of the assisted dying process.
- 49. Permitting assisted dying for adults only accords with P95/2021. Furthermore, the majority of jurisdictions that permit assisted dying do so for adults only, with the exception of Belgium and the Netherlands.
- 50. Whilst P95/2021 provided for assisted dying for adults only, the accompanying report set out that "Further consultation and research on under 18s will be undertaken prior to lodging of any associated legislation. This will include detailed consultation with the Children's Commissioner". That further consultation activity included:
 - a. Consultation with the Children's Commissioner: The previous Minister for Home Affairs corresponded with the Children's Commissioner to establish her views on the matter. The Commissioner noted concerns regarding the introduction of assisted dying legislation for all, including under 18s, citing views previously expressed by UN rapporteurs and treaty bodies. For

- example, the concluding observations of the Human Rights Committee in the Netherlands in 2009.²⁸
- b. Phase 1 and 2 public consultations: Feedback on the proposed age limit during the consultation phase indicated mixed views on the subject. 39.9% of those who responded to the survey agreed assisted dying should only be available to those aged 18 or over, 34.8% disagreed and 25.2% of respondents stated, 'don't know'.
- c. Ethical review: Ethical arguments were presented both for and against permitting assisted dying for adults only. These centred around whether or not it is unjust to deny a child who is suffering the right to choose an assisted death (if they have the competency to make such as decision) and the potential inequality of excluding children with medical conditions which result in as much suffering as an adult, who would be eligible for assisted dying. On balance, the review authors found that assisted dying should be restricted to adults.
- 51. Given the lack of strong justification either to include or exclude under 18s, these proposals accord with the 'in principle' decision of P95/2021 and only permit assisted dying for adults.

Ordinarily resident in Jersey

- 52. For the purposes of the draft law, a 'Jersey resident' will be defined as a person who has been ordinarily resident in Jersey for a minimum of 12 consecutive months in the period immediately before they make their first formal request for an assisted death.
- 53. The 12-month time limit is intended to discourage 'death tourism' (i.e., people travelling to Jersey specifically for the purposes of accessing the assisted dying service) whilst not unduly preventing access to assisted dying for those who have moved to the Island more recently.
- 54. Ordinarily resident means a person who lives in Jersey and spends all their time here except for short visits abroad on business or holiday. It does not include people who temporarily live in Jersey for work or for study or other purposes, or who are on holiday in Jersey.
- 55. The requirement to have been ordinarily resident in Jersey for at least 12 consecutive months immediately before making a first formal request will apply to all people. A person who is, for example, Jersey born but has been living elsewhere cannot bypass the 12-month ordinarily residency criteria even if they are entitled to free health care under Health and Community Services

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²⁸ Refworld | Concluding observations of the Human Rights Committee : Netherlands

Department's existing Residents and Non-Residents Charging policy HCS's charging policy (or any other equivalent policy that may be in place at the time of their assisted dying request).

Voluntary, clear, settled and informed wish to end their own life

- 56. The person's wish for assisted dying must meet all four qualifications detailed below. Their wish must be:
 - i. voluntary the assessing doctor must be satisfied that the person is making the request free from any coercion or pressure by another person
 - ii. clear the person must be able to clearly articulate their wish for assisted dying. For those who have English as an additional language, or do not use verbal communication this may be achieved using an interpreter or communication support
 - iii. settled –a person must be able to demonstrate a consistent wish for assisted dying throughout the assessment, approval and provision of an assisted death. The person's wish for assisted dying may change over time, and as such they are always in control of the process.
 - iv. informed as part of the assessment process the person must be informed both about the assisted dying process, their prognosis and any other care and treatment options available to them.

Decision-making capacity

- 57. The person must be able to demonstrate they have decision-making capacity throughout the process of assessment, approval and provision of assisted dying.
- 58. The law will set out a legal test that assessing doctors must use to determine whether a person has the capacity to decide to request an assisted death (assisted death decision-making capacity).
- 59. To demonstrate assisted death decision-making capacity the person must be able to:
 - i. understand information about the nature of assisted dying that is relevant to the decision:
 - ii. retain that information to the extent necessary to make the decision;
 - iii. use or weigh that information as part of the process of making the decision;

iv. communicate the decision in some way.

Section 7 – Assisted dying process – request, assessment and approval, provides further detail on how all criteria will be assessed.

Application of eligibility criteria

- 60. The eligibility criteria must apply at the point in time at which a person makes a first formal request for assisted dying.
- 61. If the person does not meet all the eligibility criteria, when assessed, they cannot proceed through the rest of the assisted dying process. This does not preclude them from starting the process again should there be changes in their circumstances.

Future changes to eligibility criteria

62. Any future changes to eligibility criteria will require amendments to the primary law, the law will not provide for a broad Regulation making power. This safeguard is intended to ensure that Privy Council, as well as the States Assembly, are sighted on any changes and to provide a counter to the 'slippery slope' concerns raised in some consultation feedback.

Section 4: Jersey Assisted Dying Service

This section of the report outlines how the Jersey Assisted Dying Service will operate, including the governance structures.

- 63. It is proposed that the law will set out that the Health and Social Services Minister ("the Minister") must make arrangements to establish an assisted dying service in Jersey (the "Jersey Assisted Dying Service").
- 64. As described in these proposals the Jersey Assisted Dying Service will be managed and delivered by the Health and Community Services Department ("HCS"). This accords with most other jurisdictions where assisted dying services are also delivered as part of the public health system Switzerland and Germany being the exceptions.
- 65. Notwithstanding the intention that the service is delivered by HCS, the law should not preclude the Minister from making arrangements for a different entity to provide the Jersey Assisted Dying Service if, as some point in the future, the Minister were to be satisfied that another entity were better placed to manage and deliver the service, and that the entity would do so in accordance with the law.
- 66. The law must, therefore, provide a power to amend the provider by Regulation. These Regulations will need to also provide for amendments to governance and oversight arrangements associated with the Service, in the event the provider changes. This will include arrangements related to the establishment of Assisted Dying Assurance and Delivery Committee (see paragraph 72, below).
- 67. The law will provide that:
 - a. no other person or entity other than the Jersey Assisted Dying Service can provide an assisted dying service in Jersey, and that
 - b. no person can charge for provision of an assisted dying service in Jersey, including the Minister.
- 68. In placing a duty on the Minister to make arrangements to establish an assisted dying service, the law must recognise that there may be circumstances in which the Minister cannot make the necessary arrangements (for example, if the assisted dying service cannot be appropriately and safely staffed because professionals do not wish to work in the service, or there are insufficient public funds to deliver the service).
- 69. The Jersey Assisted Dying Service, as established, will:
 - a. provide a point of contact for anyone who wants information about assisted dying or is considering requesting an assisted death

- b. provide a point of contact and information for any professional who wants information about assisted dying in order to support a patient / client
- c. support people requesting assisted dying to navigate the process
- d. support the loved ones of people who have requested an assisted death
- e. coordinate and deploy the professionals who will deliver the assisted dying process, including assessments to determine eligibility in law, associated decision-making and preparations, and administration of the assisted death substance
- 70. The Jersey Assisted Dying Service may be accessed by any person who is eligible to access free non-emergency hospital care in accordance with the Minister's published access criteria (the access criteria for free non-emergency hospital care are currently set out in the HCS Residents and Non-Residents Charging policy). Where a person is:
 - a. not entitled to access free non-emergency hospital care in accordance with the Minister's criteria the person will not be able to access the Assisted Dying Service, this includes not being able to access it as a paid-for service as per other HCS non-emergency hospital services
 - b. is entitled to access free non-emergency hospital care in accordance with the Minister's criteria, this does not entitle the person to an assisted death unless they meet all the criteria in law.
- 71. The service will be a free service regardless of whether it is provided in an HCS facility or another location, for example, a person may be seen by assessing doctors and have an assisted death at their home or in another location (see after paragraph 426, approval of location).

Assisted Dying Assurance and Delivery Committee

- 72. The law will provide that an *Assisted Dying Assurance and Delivery Committee* ("the Committee") must be established by the Minister and that the functions of the Committee must include:
 - a. establishment of the Jersey Assisted Dying Service, including:
 - development and approval of the assisted dying training programme, professional guidance, service and clinical protocols
 - approval of the competency frameworks for all assisted dying practitioners and the Care Navigator
 - establishment and maintenance of a register of assisted dying practitioners

- b. oversight of the Jersey Assisted Dying Service, including:
 - development of, and assurance of compliance with, clinical standards
 - development service standards, including target maximum timeframes for the Jersey Assisted Dying Service
 - oversight of service safety and quality, through continuous monitoring of the service
 - oversight of the management and response to complaints and / or potential patient safety concerns related to the service
 - providing assurance to the Minister and the public about patient experience, clinical safety and service quality
 - approving the retention schedule for all records held by the Jersey Assisted Dying Service
 - producing and publishing an annual report on assisted dying in Jersey
 - establishment of an Assisted Dying Review Panel. [see section 10, Regulation and oversight]
- 73. The law will provide the Committee with powers to:
 - a. investigate matters relating to practice of registered assisted dying professionals, including powers of suspension and investigation
 - b. share information about the practice of registered assisted dying professionals with relevant third parties (for example, UK professional regulatory bodies, the Attorney General)
- 74. In developing the training programme, professional guidance and the service and clinical protocols, the Committee will have a legal duty to consult with relevant professional bodies (for example, in developing the prescription and administration protocols for the assisted dying substance, the Committee must consult with the Chief Pharmacist, the General Pharmaceutical Council, the Royal Pharmaceutical Society and the Medicines and Healthcare Products Regulatory Agency). [See Appendix 3 -Forms and guidance, for full list of guidance and protocols to be developed by the Committee]
- 75. The law will provide that the Committee must be established and must operate in accordance with its terms of reference, which must be prescribed by Order of the Minister. The Order must be made prior to the commencement of the Jersey Assisted Dying Service.

- 76. The terms of reference for the Committee will set out:
 - a. procedures related to the delivery of the Committee's duties and functions
 - b. matters relating to Committee membership and the appointment of members.
- 77. Prior to making the Order (or subsequent amendments to the Order), the Minister must consult the Jersey Care Commission, the Chief Officer of the Health and Community Services Department, and any other person who the Minster determines should be consulted. (Note: this will include the Chair of the Health and Community Service Advisory Board where an Advisory Board is established).
- 78. It is envisaged that the Committee will be established as a sub-committee of the Health and Community Services Advisory Board, and will report via the Board to the Minister unless the Advisory Board has been disbanded in which case the Committee will report directly to the Minister. In the event that an entity other than HCS is delivering the Jersey Assisted Dying Service, the law will need to provide a power to amend the Committee provisions by Regulations.
- 79. The Terms of Reference will set out the minimum and maximum number of Committee members. The Minister will appoint committee members by Ministerial Decision (except for where the member is a relevant professional lead, in which case they will automatically be appointed to the Committee).
- 80. The following relevant professional leads (or the equivalent post holders) will be members of the Committee:
 - a. Chief Officer, HCS
 - b. Chief Nurse
 - c. Medical Director
 - d. Chief Pharmacist
 - e. Director of Mental Health & Adults Social Care and Chief Allied Health Professional (or equivalent)
- 81. Other committee members will include:
 - a. representatives from non-HCS services that provide care to people who are at end-of-life, for example; hospice, care homes and home care providers
 - b. persons who have significant, demonstrable experience of oversight and assurance of clinical service provision and who are not an employee of HCS

- c. patient representatives with lived experience of palliative care and / or end of life care in a personal capacity or by supporting loved ones through the process.
- 82. The law will provide that the Chair of the Committee, who must be appointed by the Minister, must be an independent person (i.e., they cannot be an employee of HCS or another service that provides end-of-life or palliative care service or affiliated to any assisted dying campaign group) and must have demonstrable, significant experience of oversight and assurance of clinical service provision. In the event that the Committee is a sub-committee of the Health and Community Services Advisory Board, the Chair of the Committee will be a Non-Executive Director of the Health and Community Services Advisory Board. This may require the appointment of an additional Non-Executive Director to the Advisory Board.
- 83. The Committee may seek specialist advice from non-members who may attend meetings on a regular or ad hoc basis, for example HCS Associate Director of Quality and Safety.
- 84. The Minister may determine, by Ministerial Decision, any remuneration provided to the Chair of the Committee or to any other members of the Committee (who are not relevant professional leads).

Annual report on assisted dying in Jersey

- 85. The Committee will have a duty to publish an annual report on assisted dying. It will set out:
 - a. numbers of 'Route 1 terminal illness' and 'Route 2 unbearable suffering' assisted dying requests, approvals (plus appeals) and assisted deaths (including as % of overall deaths in Jersey)
 - b. profile of persons requesting an assisted death, plus profile of those approved and those who had an assisted death (age, gender, physical medical condition, use of palliative and end of life care, nature of suffering reported)
 - c. matters relating to assessment process (routes for determining voluntary nature, number of supporting assessments by different professional groups etc.)
 - d. matters relating to approval (for example numbers of consent to proceed, and waiver of final confirmation of consent)
 - e. matters relating to assisted deaths (mode of assisted death plus any associated intervention, time between approval granted and assisted death)
 - f. uptake of support services for professionals plus family and friends (where known).

- 86. The Committee will consult the Medical Officer for Health to confirm the data to be presented in the report and agree the methodology for compiling the data.
- 87. The data included in the report will support identification of any trends or potential issues. This could for example, potentially identify groups of people with similar characteristics who may be more or less inclined to request assisted dying and as such may indicate requirements for changes to existing support or treatment services.
- 88. The annual report will also publish high-level data on the work of the Assisted Dying Review Panel. [see section 10, Regulation and oversight]
- 89. The annual report will be suitably anonymised and steps will be taken to ensure that people cannot be identified. It must be appreciated, however, that a combination of small population size plus the recording of the cause of death in the public domain may, in some cases, result in the identification of an individual. Therefore, it may be that when preparing the annual report a decision is made not to publish some demographic details in order to protect anonymity and privacy.

Section 5: Health and care professionals – right to refuse / conscientious objection, discussions with patients and registration

This section of the report details the right of professionals to refuse to directly participate in assisted dying, how professionals must conduct discussions with patients, and the Jersey Assisted Dying Service registration process, including qualification and training requirements.

Right to refuse to directly participate in assisted dying / conscientious objection

- 90. In debating P95/2021 the Assembly agreed, in principle, that 'the law should provide for a conscientious objection clause so that any registered nurse, medical practitioner or other professional is not under a legal duty to participate in assisted dying.' A right to conscientious objection ensures that people are free to act in accordance with their own personal beliefs about assisted dying.
- 91. In accordance with the Assembly's decision, the Law will explicitly provide that no person can be compelled to *directly* participate in the assessment, approval or delivery of an assisted death either on the grounds of conscientious objection or any other grounds i.e., there is a right to refuse to directly participate on any grounds (for example, emotional impact on the professional or potential impact on the professional's other patients) not just on the grounds of conscience or belief.
- 92. Refusal on the ground of conscience has been extended to any grounds in light of feedback back from key stakeholders, in particular the BMA.²⁹
- 93. The Law will provide for a right to refuse to <u>direct</u> participation only. This mirrors the provisions of the Termination of Pregnancy (Jersey) Law 1997 (see Note below), except that the ground for to objection will be wider than just conscientious objection and, in these proposals, includes objection on any grounds. This is on the basis that, if the intent of the law is to provide a safe, compassionate, and accessible assisted dying service, any objection clause that is cast 'too wide' [i.e. allows for the right to refuse to non-direct participation] could potentially have the effect of negating the underlying policy intent (i.e., the service could not be delivered if ancillary tasks were not undertaken).
- 94. Providing the right to refuse direct participation only would broadly mean that staff and service providers:
 - a. could refuse, on the basis of conscientious objection or any other grounds,
 to:
 - support a person to access the assisted dying service, including providing them advice, counselling, or advocacy support

²⁹ bma-letter-to-deputy-tom-binet-feb-2024.pdf

- undertake any of the specified roles (i.e., refuse to act as Care Navigator, Coordinating Doctor, Independent Assessing Doctor, Pharmacy Professional or Administering Practitioner)
- be present at the time of administration of the assisted dying substance, or directly support the administration
- sit on the Tribunal or directly support the Tribunal (for example, act as the Tribunal Secretary)
- undertake a supporting assessment to inform the assessing doctor's determination of eligibility for assisted dying (for example pulmonary function tests, carried out by a physiotherapist or an assessment to determine decision-making capacity by a psychiatrist or psychologist).
- b. could <u>not refuse</u>, on the basis of conscientious objection or any other grounds, to carry out tasks which are within the normal duties of their work, and which are not directly related to the assessment or delivery of an assisted death, for example:
 - providing usual nursing, medical or personal care to a person who
 happens to have requested an assisted death (for example, a care
 home could not refuse to care for a resident because that resident
 wants an assisted death; an ambulance or patient transport driver
 could not refuse to transport a patient to an assisted dying
 appointment)
 - related administrative tasks (for example, providing patient records to an assessing doctor, booking appointments for additional assessments, ordering equipment or undertaking residency checks)
 - related management or governance tasks (for example, refusing to act as a Responsible Officer for an assisted dying doctor, or refusing to undertake financial planning tasks associated with the delivery of the service)
 - delivery of equipment or medical supplies that may be used for the purpose of an assisted dying assessment or the delivery of an assisted death.

Note: Termination of Pregnancy

A conscientious objection clause is currently provided for under Article 5 of the Termination of Pregnancy (Jersey) Law 1997 which mirrors UK's 1967 Abortion Act. In 2014, the Supreme Court ruled that the conscientious objection clause should be interpretated as being 'narrow' in scope as opposed to 'wide' scope i.e., that

participation in termination of pregnancy means "actually taking part" or performing the tasks involved in the course of treatment which would broadly include the administration of drugs to induce labour, the medical and nursing care associated with labour and giving birth but would not include, for example, the ordinary nursing or pastoral care of a patient, the associated administrative tasks or the hospital managers who determine how the service is organised.³⁰

- 95. For clarity, whilst supporting assessments used to inform eligibility for assisted dying would constitute direct participation (and therefore be covered under a right to refuse direct participation), providing pre-existing information on request test results, notes on prognosis etc. would not constitute direct participation, and a health and care professional would not be covered by a right to conscientiously object. [In addition, this pre-existing information would be held on a patient's medical record, and they would be able to make a Subject Access Request under the Data Protection (Jersey) Law 2018, in order to view any information that is held about them.]
- 96. Regarding a number of the tasks noted in paragraph 94 above, a person requesting assisted dying would have a right to privacy and patient confidentiality. Therefore, if a person is being transported to hospital for an assisted dying assessment, this would not need to be known by the person driving them. Similarly, a person ordering medical equipment such as a syringe pump, would likely not be aware that equipment is being ordered for the purpose of an assisted death, as opposed to any other form of medical care or treatment.
- 97. If a task is within the agreed scope of a right to refuse clause either on the grounds of conscientious objection or any other grounds, a care professional can refuse to directly participate. However, in doing so, they must not:
 - a. unfairly treat a person who wants an assisted death
 - b. deny a person access to appropriate medical treatment or services
 - c. cause distress to the person.
- 98. The law will require the Minister to bring forward Right to Refuse and Conscientious Objection Guidance setting out how care professionals who object to assisted dying should interact with people who want information about an assisted death or who have requested an assisted death. The Right to Refuse and Conscientious Objection Guidance will stipulate that the care professional:
 - a. if requested, must provide the person the contact details of the Jersey Assisted Dying Service

³⁰ *Greater Glasgow Health Board (Appellant) v Doogan and another (Respondents) (Scotland) (supremecourt.uk)

- b. must inform the person of their conscientious objection
- c. must not express their personal beliefs on assisted dying to the person in a way that exploits their vulnerability or are likely to cause them distress.
- 99. Where the healthcare professional is registered with a professional regulatory body they will, in any event, need to operate in accordance with any professional standards the body (and any other relevant body) has in place with regard to conscientious objection (see note below), as failure to do so may result in a referral being made to their professional regulatory body.

Note:

UK Professional Regulators' guidance on conscientious objection

The NMC Code sets out that professionals must: 31

- a. tell their manager, colleagues and the person receiving care that they have a conscientious objection
- b. arrange for a qualified colleague to take of responsibility for the person's care
- c. not express their personal beliefs in an inappropriate way

The GMC's guidance sets out that professionals must do their best to make sure that patients are aware of the objection in advance and inform employers and colleagues about their conscientious objection. ³² They must also:

- tell the patient they have the right to discuss the matter with another practitioner who does not hold the same objection.
- make sure that the patient has enough information to arrange to see another doctor who does not hold the same objection, or support them to arrange to see another doctor
- be respectful of the patient's dignity and views

They must not:

• obstruct patients from accessing services or leave them with nowhere to turn.

³¹ Conscientious objection - The Nursing and Midwifery Council (nmc.org.uk)

³² Personal beliefs and medical practice - professional standards - GMC (gmc-uk.org)

- 100. The Right to Refuse and Conscientious Objection Guidance to be brought forward by the Minister will apply to:
 - a. health and care professionals who are not registered with professional regulatory bodies OR are registered with professional regulatory bodies that do not have professional standard / guidance on conscientious objection, and will provide them with a framework for operating within, and
 - b. health and care professionals who are registered with professional regulatory bodies that do have professional standards / guidance on conscientious objection, and this guidance will accord with (as opposed to contradict) the standards set out by their professional regulatory body.
- 101. For the purposes of clarity, it will not be an offence <u>not to comply</u> with the Right to Refuse and Conscientious Objection Guidance. However, depending on the circumstances, a failure to comply may lead to a referral to a professional regulatory body if the fitness to practise concerns could amount to a serious departure from their professional standards. It may also result in investigation by an employer.
- 102. The right to objection will also be extended to premises operators to refuse to allow for an assisted death on their premises. This right will be provided to the registered providers (for example the trustees or board of directors of an organisation) of adult care home services regulated by the Jersey Care Commission under the Regulation of Care (Jersey) Law 2014 (which includes care homes, nursing homes and any other form of regulated residential care provision). This right will not extend to any Government of Jersey premises or private landlords.
- 103. The right for premises operators to object to assisted dying, only extends to the provision of an assisted death on the premises. It does not extend to other steps in the assisted dying process, such as making a request for an assisted death, having an assessment, or the approval or planning of an assisted death. So, for example a resident of a care home could have an eligibility assessment or assisted death care planning meeting on the premises, but the care home provider may choose not to permit a resident to have an assisted death in their room.
- 104. In some cases, premises operators will support their residents or patients end-of-life wishes and allow for an assisted death on their premises but, if they choose not to, the Jersey Assisted Dying Service would liaise with the person to identify a suitable alternative location.

Discussion of assisted dying with patients

105. Other than in relation to providing a right to refuse/conscientious objection the law will remain 'silent' on health care professionals discussing assisted dying with their patients – that is to say, the law will neither:

- a. require health and care professionals to raise the subject of assisted dying with a patient or client whom the professional thinks may be eligible for an assisted death, nor
- b. prohibit health and care professionals from talking to their client / patient about assisted dying, in the context of the patient's care and treatment options, even where the client / patient did not raise the subject in the first instance.
- 106. Whilst assisted dying should never be 'recommended', health and care professionals do need to be able to engage in open and informed conversations about end-of-life options which may, in some cases, include assisted dying. There is a balance to be struck between the risk that a patient may feel that assisted dying is being suggested to them as a preferred option, and the risk that a patient is unable to have an informed discussion with a trusted professional about their end-of-life options, or the risk that access to information is inequitable.
- 107. The laws in Canada and certain Australian states are similarly 'silent', neither prohibit or require a health and care professional to raise the subject.
- 108. In New Zealand, the law actively prohibits all or certain health professionals from initiating any discussion, though it is understood this position will be considered in a 2024 review of the legislation as it is perceived be some as a 'gagging' clause which gives rise to two key disadvantages:
 - a. it can generate uncertainty and confusion amongst professionals as to whether the topic is being raised by a patient or not, which results in a reluctance to discuss the topic openly
 - b. it creates an inequality in access to information for certain groups particularly those with English as an additional language and those with additional communication support needs.
- 109. However, whilst an explicit requirement to tell people about assisted dying may improve equity of access to information, it may also have unintended consequences, particularly around:
 - the sensitivity and nuance as to when is the best time for a conversation about assisted dying
 - the doctor-patient relationship and fine balance of a practitioner providing a patient with relevant information vs. being perceived to make a recommendation.
- 110. Therefore, whilst the law will neither prohibit nor require professionals to raise the subject of assisted dying with patients, it will require the Minister to bring

forward non-statutory guidance for health and care professionals on how to have appropriate conversations about assisted dying with patients.

- 111. The Appropriate Conversations Guidance will support health and care professionals to manage conversations around assisted dying on an individual level. It will set out the circumstances in which it may be appropriate to raise the issue of assisted dying with a client / patient and the circumstances in which it should not be raised, for example:
 - it may appropriate to raise with a client / patient who has a terminal illness, as part of an 'in the round' conversation alongside consideration of all other end of life care and treatment options, including palliative care.
 - it would not be appropriate to raise with a client / patient who does not have a terminal illness but may be eligible under 'Route 2 unbearable suffering', as highlighted in the Assisted Dying in Jersey Ethical Review:

"When a person is not approaching their natural death, offering AD would convey to the person (who may potentially have years or decades of life remaining) the message that death is a reasonable option for them. Many people with disabilities would consider this to be offensive, as it would convey a message that death is a reasonable option for persons faced with a disability or chronic illness. There is a heightened concern about how this may impact on resilience."

For the purposes of clarity:

as per the Conscientious Objection Guidance - it will not be an offence not to comply with the Appropriate Conversations Guidance but failure to comply may result in action or investigation by an employer or a referral being made to a professional regulatory body if it could amount to a serious departure from their professional standards.

a. failure to comply may result in action or investigation by an employer or a referral being made to a professional registration body if it could amount to a serious departure from their professional standards.

and

- b. whilst the Guidance may stipulate circumstances in which a health and care professional should not raise the subject of assisted dying, there is nothing that should prevent the health and care professional discussing the matter if the patient raises the issue themself (other than any conscientious objection on the part of the professional).
- 112. In addition to publishing guidance, the law will require the Minister to make provision for training on appropriate conversations to made available free of charge to all on-island health and care professionals.
- 113. Both the Nursing and Midwifery Council (NMC) and the General Medical Council (GMC) in their written responses to the Phase 2 consultation supported the position that the law is 'silent' on the matter of health and care professionals

raising the issue of assisted dying with clients / patients, and supported the development of training and guidance.

Protections for health and care professionals

114. During the law drafting process, consideration will be given to bring forward legal protection so that health and care professionals cannot be discriminated against on the basis of their decision to either participate, or not participate, in assisted dying. This may also include the provision of safe access zones to protect both professionals and service users from potential harassment and/or abuse. A safe access zone is a designated area where protests and demonstrations are expressly prohibited.

Health and care professionals' involvement in assisted dying

- 115. As set out in Section 4 Jersey Assisted Dying Service, the law will set out no other person or entity other than the Jersey Assisted Dying Service can provide an assisted dying service in Jersey. Therefore, any professional who is directly involved in the provision of assisted dying in Jersey will be required to work for the Jersey Assisted Dying Service.
- 116. If the Jersey Assisted Dying Service is provided by HCS (as intended), that professional will also need to be engaged by HCS via a contract of employment or a contract for services that enables them to work in the Jersey Assisted Dying Service. (Note: this is contractual matter, not a matter for law).
- 117. The law will provide that, in order to work for the Jersey Assisted Dying Service, the professional must register as an assisted dying practitioner.
- 118. The Committee will hold statutory responsibility for maintaining a register of health and social care professionals who are approved to work in the Jersey Assisted Dying Service as assisted dying practitioners. The Jersey Assisted Dying Service will, on behalf of the Committee, require all professionals seeking to work in the Service to register with it. All professionals will be required to renew their registration annually.

Registration as an assisted dying practitioner

- 119. The law will provide for the assisted dying practitioner registration arrangements including:
 - a. registration information
 - b. registration application procedures
 - c. training and qualification requirements
 - d. suspension and cancellation of registration procedures

- e. the powers and duties of the Jersey Assisted Dying Service to share information with other relevant bodies (for example, UK professional regulatory bodies, States of Jersey Police)
- 120. The Jersey Assisted Dying Service will keep a register with the details of all professionals who have registered as an assisted dying practitioner. These details will include:
 - a. the professional's name
 - b. name of their UK professional regulator and UK registration number (where applicable)
 - c. their Jersey Care Commission registration number (where applicable)
 - d. any declared conflicts of interest
 - e. their assisted dying service role/s (e.g.: Care Navigator, Assessing Doctor)
 - f. details of participation and completion of Assisted Dying training, and dates for refresher training
 - g. date of entry on the Assisted Dying register
 - h. date of removal from assisted dying register (and reason for removal from register).
- 121. The purpose of registration as an assisted dying practitioner is to maintain a record of appropriately qualified professionals who may work for the Jersey Assisted Dying Service.
- 122. Full registration requirements (as an assisted dying practitioner) for professionals are set out below. In order to register as an assisted dying practitioner, a professional must be registered with the JCC and appropriate UK professional regulatory body, demonstrate the skills outlined in the assisted dying practitioner competency framework and have successfully completed mandatory training (and refresher training).
- 123. The law will set out that details of the application to register should be in the form required by the Committee and be accompanied with such information as the Committee requires, outlined in paragraph 120 above.
- 124. A professional may at any time request to cancel their registration as an assisted dying practitioner.
- 125. Professionals will be required to renew their registration on an annual basis. And in addition, advise and update the Jersey Assisted Dying Service if there

- have been any changes to the details held by the register, outside of the renewal period.
- 126. The law will provide that a person registered as an assisted dying practitioner will commit an offence if they fail to inform the Service that their registration with the JCC has been suspended or cancelled. [See section 11, Offences]
- 127. The Jersey Assisted Dying Service must cancel or suspend a professional's registration as an assisted dying practitioner, if that person's registration with the JCC and/or their relevant professional body is cancelled or suspended.
- 128. The Jersey Assisted Dying Service may also cancel or suspend a professional's registration as an assisted dying practitioner if:
 - a. they are found not to have met all the registration requirements, including successful completion or renewal of the mandatory training
 - b. any fitness to practise issues arise, including if as a result of their work for the Jersey Assisted Dying Service
- 129. The register will be confidentially held (i.e., it will not be published) to protect the right to privacy of professionals in a small island jurisdiction. However, access to the register will be available to the Chair of the Committee, as the Committee holds the register. In addition, information about registrants can be shared with relevant organisations and office / post holders including the Jersey Care Commission (JCC), the Chair of the Committee, the Director of Public Health, Chief Nurse, Medical Directors, Chief Pharmacist and Responsible Officers.
- 130. If there are any concerns with the practise of a person on the register, then the Jersey Assisted Dying Service may provide to the person's UK professional regulatory body, and any other relevant authority, including the States of Jersey Police, any registration information that the Assisted Dying Service deems relevant, whether or not in response to a request from the UK professional regulatory body.
- 131. On adoption of the assisted dying law, during the implementation period, the Committee will work with the Jersey Care Commission and the UK professional regulatory bodies to produce clear guidance on matters to be referred to the UK professional regulatory bodies, this will include but is not restricted to:
 - a. agreed process for referrals to professional regulatory body
 - b. concerns that meet the threshold for referral including concerns:
 - i. that pose a serious risk to people who use the service

- ii. where local action can't effectively manage any ongoing risks to people who use the service
- requiring the UK professional regulatory bodies to take action to protect public confidence in the professions and uphold standards
- c. notification where a professional is removed from the register due to fitness to practise matters
- 132. In addition to the register not being public, the law will also provide that the names of individual professionals involved in any specific assisted death cannot be made public (see section 11, Offences).

Jersey Assisted Dying Service – contracting assisted dying practitioners

- 133. From an operational perspective, HCS will engage the professionals required to deliver the Jersey Assisted Dying Service. They may be engaged on contract for services or contract of employment basis, and may include:
 - a. HCS employees
 - b. HCS bank staff
 - c. professionals on special contracts (for example, HCS may contract local GPs or registered nurses (level 1) employed by other on-island organisations, or off-island professionals to fulfil any of the roles described below).
- 134. Where the professional is engaged as part of their existing contract of employment with HCS, it may be that an addendum to their contract will be required to set out their specific duties in relation to work for the Jersey Assisted Dying Service.
- 135. At this time, it is not envisaged that locums and agency staff will be engaged by the Jersey Assisted Dying Service. A reason for this being that as they would not be directly employed by HCS, they would require their own indemnity insurance arrangements to cover any assisted dying work. It is envisaged that indemnity cover for all assisted dying practitioners will be provided by HCS (this can only be confirmed when insurers have reviewed the draft assisted dying law see Section 1 Background). This arrangement would not exclude, however, professionals currently working within HCS as locums in other areas, from being engaged on a separate fixed-term contract to work as an assisted dying practitioner.
- 136. HCS will ensure that arrangements are in place to ensure that all professionals engaged in the Jersey Assisted Dying Service meet the relevant competency framework developed by the Committee.

Note: Staffing

It is not known how many professionals currently working in Jersey would be prepared to work for the assisted dying service. During the course of the consultation process, a number of professionals pro-actively stated that they would, in principle, work for the service, whilst a number made it clear that they would not.

It is possible that the Jersey Assisted Dying Service may be unable to recruit or contract the necessary staff (although it is important to recognise that this eventuality has not occurred in any other jurisdiction that permits assisted dying). In the event this were to happen, whilst assisted dying would be permitted in law, there would be no service and hence people could not have assisted deaths in Jersey.

Therefore, in placing a duty on the Minister to provide the Jersey Assisted Dying Service, the law must also provide that the Minister can only do so if the service can be appropriately and safely staffed.

The Ethical Review authors recommend that once the assisted dying proposals have been confirmed [i.e. *after* the Assembly debate on this proposition], work is undertaken to survey local health and care professionals regarding their willingness to participate in assisted dying. This would support a better understanding of the potential implementation challenges and the likely requirement for 'off island' practitioners prior to the approval of a draft law. This in-depth survey work cannot be meaningfully undertaken until after the detailed proposals have been developed, as professionals have made clear that they need a full understanding of the proposals to inform their decision.

137. Due to the nature of the workforce in Jersey there is a need to ensure flexibility in the deployment of professionals engaged in the assisted dying process. Therefore, a doctor could be deployed / contracted to undertake different roles in the service, for example a doctor could act as a Coordinating Doctor for person A and as the Independent Assessment Doctor for person B.

Roles within the Jersey Assisted Dying Service

- 138. The specific 'assisted dying practitioner' roles to be undertaken in relation to assisted dying as listed in 'Terms used' will include:
 - **Coordinating Doctor** the doctor who: undertakes the first assessment of the person who has requested an assisted death, coordinates the whole assessment process; makes the decision to approve the request (prior to confirmation by Tribunal for 'Route 2' requests) or decline the request.
 - **Independent Assessment Doctor** the doctor who undertakes the second, independent assessment of the person who has requested an assisted death.
 - **Second Opinion Doctor** the doctor who undertakes an additional first or second assessment, if requested by the person.

- Multidisciplinary team (MDT) member an MDT will be formed to support the assessment process for each person who requests an assisted death. In addition to the assessing doctors, the MDT may include a registered nurse (level 1), social worker and any other relevant allied health professionals (e.g., a speech & language therapist).
- Pharmacy Professionals pharmacists and pharmacy technicians who have registered with the Jersey Assisted Dying Service. Will prepare and dispense the substance used in assisted dying, will work within the Hospital Pharmacy.
- Administering Practitioner the doctor or registered nurse who will directly
 administer the substance used in assisted dying or support the person to selfadminister the substance.
- assessing doctors the Coordinating Doctor and the Independent Assessment
 Doctor (plus the Second Opinion Doctor, where relevant) are collectively
 referred to as "assessing doctors". They will assess the person who has
 requested an assisted death to determine if they meet the statutory criteria. They
 work within the Jersey Assisted Dying Service.
- 139. In addition, the Jersey Assisted Dying Service will engage non-clinical staff as **Care Navigators**, who will support the person requesting an assisted death and support the Coordinating Doctor to coordinate process. They will act as the initial point of contact for information and enquiries into the Jersey Assisted Dying Service.
- 140. Other attending practitioners and carers is the term used to describe service providers (for example, a domiciliary care provider, a community or hospital nurse, a GP) who may be involved in care or treatment of the person who has requested an assisted death but who are not directly involved in the assisted dying request, assessment, approval or administration process (except for, where they are asked to undertake a supporting assessment, or provide information or advice to support an assessment or determination [and do not conscientiously object to doing so].)

Assisted Dying training and qualifications

Competency frameworks

- 141. The competency frameworks will set out the skills, knowledge and behaviours required to practise as an assisted dying practitioner or Care Navigator.
- 142. All assisted dying practitioners must be able to demonstrate they meet the required competencies prior to registering as an assisted dying practitioner. The frameworks will vary across the different roles for example, the Pharmacy Professional competency framework will differ from to the Assessing Doctor competency framework.

- 143. The competency frameworks will be developed by the Committee in consultation with the relevant stakeholders, for example the UK professional regulatory bodies and professional membership organisations. It is anticipated that the frameworks will cover:
 - a. professional values and behaviours
 - b. professional skills (including practical skills, communication and interpersonal skills, and clinical skills)
 - c. professional knowledge
 - d. specific capabilities including: safeguarding vulnerable groups, patient safety and legal and ethical aspects of care.

Assisted Dying training

- 144. All assisted dying practitioners (i.e., professionals who are registered with the Jersey Assisted Dying Service) must have successfully completed the bespoke training programme prior to registration.
- 145. The training programme will be developed by the Committee. In developing the training, the Committee will look to work with other jurisdictions who have experience in developing mandatory assisted dying training.
- 146. The training programme will cover, in detail:
 - a. the requirements, duties, competencies and obligations associated with each role
 - b. an overview and understanding of all the different roles within the assisted dying process
 - c. the assisted dying legislative provisions
 - d. the assisted dying guidance and all associated clinical and service provision protocols
 - e. specific training on assessing eligibility (including determining decisionmaking capacity) and administering an assisted death (including selfadministration and practitioner administration)
 - f. practitioner safety and wellbeing.

[See Appendix 4 – Outline of mandatory training, for further detail]

147. The training will be valid for a period of 3 years, after which, practitioners will be required to undergo refresher training.

Assessing Doctor

- 148. Any doctor undertaking the role of assessing doctor (Coordinating Doctor, Independent Assessment Doctor or Second Opinion Doctor) must:
 - a. be registered with the JCC to work in Jersey, and more than 12 months post full GMC registration; and
 - b. have completed assisted dying training; and
 - c. be able to demonstrate the skills outlined in the assisted dying practitioner competency framework which will be developed and published by the Assisted Dying Service Assurance and Delivery Committee; and
 - d. have opted-in to work as an assisted dying practitioner and registered with the Jersey Assisted Dying Service.
- 149. The Coordinating Doctor, the Independent Assessment Doctor and Second Opinion Doctor are not required to be an expert / specialist in the medical condition of the persons they are assessing for an assisted death but, they must seek opinion of experts as required.

Administering Practitioner

- 150. The role of Administering Practitioner will be undertaken by a doctor or a registered nurse who must:
 - a. be registered with the JCC to work in Jersey, and more than 12 months post full GMC/NMC registration; and
 - b. have completed assisted dying training; and
 - c. be able to demonstrate the skills outlined in the assisted dying practitioner competency framework which will be developed and published by the Assisted Dying Service Assurance and Delivery Committee; and
 - d. have opted-in to work as an assisted dying practitioner and registered with the Jersey Assisted Dying Service.
- 151. It is anticipated that the roles of physician associates (PAs) and anaesthesia associates (AAs) will, in future, be regulated and professionals will be able to register as PAs and AAs with the GMC and, subject to Assembly agreement, with the JCC. At this point in time, it may be that these professions will also be able to undertake the role of Administering Practitioner, subject to meeting all other requirements outlined in this section. The assisted dying law will be drafted as to allow for this.

152. The law will provide that a doctor may not be registered as an assisted dying practitioner if, at the point of doing so, the doctor does not have a named responsible officer for the purpose of GMC revalidation. A responsible officer is a doctor who helps to ensure the conduct and performance of doctors working in their local area and who makes recommendations to the GMC about their fitness to practise and whether they should be revalidated as a doctor.

Pharmacy Professional

- 153. The role of Pharmacy Professional will be undertaken by a dispensing pharmacist or pharmacy technician who must:
 - a. be registered with the appropriate professional regulatory body in Jersey (currently the Chief Pharmacist), and more than 12 months post full GPhC (General Pharmaceutical Council) registration; and
 - b. have completed the Pharmacy Professionals assisted dying training
 - c. be able to demonstrate the skills outlined in the assisted dying practitioner competency framework which will be developed and published by the Assisted Dying Service Assurance and Delivery Committee; and
 - d. have opted-in to work as an assisted dying practitioner and registered with the Jersey Assisted Dying Service.

Care Navigator and Multidisciplinary Team members

- 154. Care Navigators will be required to complete the assisted dying practitioner training, demonstrate the skills outlined in the assisted dying practitioner competency framework. As non-clinical staff, they will not be required to register with the JCC or other professional regulatory body.
- 155. Multidisciplinary Team member roles will be undertaken by health and care practitioners who must:
 - a. be registered with the JCC to work in Jersey, and more than 12 months post full registration with the GMC/NMC/HCPC or other relevant professional registration body; and
 - b. have completed assisted dying training; and
 - be able to demonstrate the skills outlined in the assisted dying practitioner competency framework which will be developed and published by the Committee; and
 - d. have opted-in to work as an assisted dying practitioner and registered with the Jersey Assisted Dying Service.

Support for professionals

- 156. It is known from other jurisdictions that supporting someone to end their own life has a direct impact on the professionals involved, even though those professionals are committed to supporting people in their choices. The Committee will develop and approve a support services package that will support assisted dying practitioners to process and reflect on the emotions associated with assisting a person to die. It is envisaged that this will include:
 - a. access to psychological support
 - b. professional support including:
 - clinical supervision
 - debriefing
 - peer support
 - networking sessions including with practitioners with experience in other jurisdictions.
- 157. The support systems would be available to both involved professionals (i.e., those who are directly involved in the assisted death) and other attending practitioners and carers (i.e., those who are caring for a person who chooses to have an assisted death).

Section 6: Assisted dying process overview

158. This section provides an overview of the formal steps of the assisted dying process including the minimum timeframes for the process and matters that apply to all steps in the process.

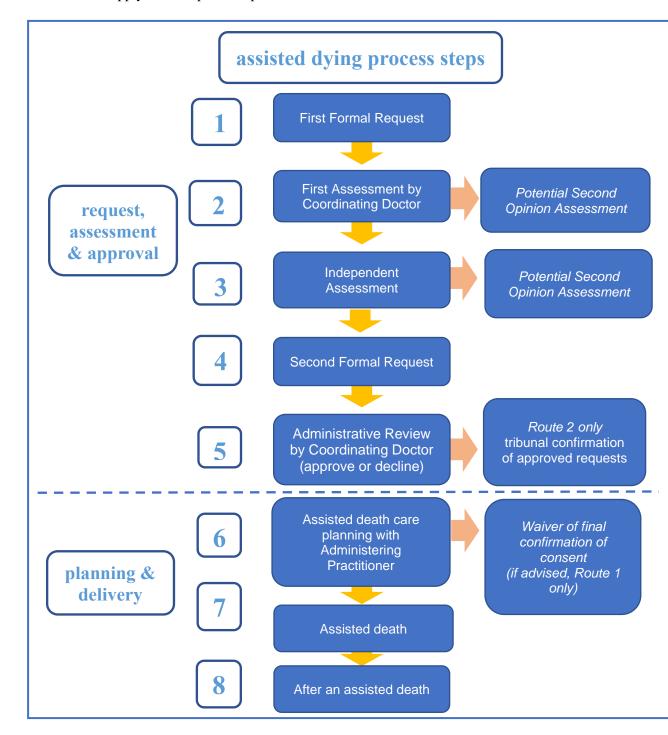


Figure 1 - Assisted dying process: overview of steps

Matters that apply to all steps in the process

Proceeding through the steps / timeframe

- 159. The assisted dying process includes 8 distinct steps. Step 1 to Step 5 are part of the request and assessment process; Steps 6 and 7 cover the planning and provision of an assisted death; Step 8 takes place after the assisted death.
- 160. The person requesting the assisted death is in control of the pace of the process:
 - each step in the process can only be initiated by the person expressing a
 wish to proceed to that step and that wish being recorded on a Step
 Transition form
 - b. the person may slow, pause or withdraw their request at any point in the process

Step Transition form

- 161. The Step Transition form will be prescribed by Order by the Minister.
- 162. It must be completed by either the Care Navigator or the Coordinating Doctor before commencing the next step (Steps 1 to 6 only) and must be signed by the person as it will record their wish to move to the next step of the process.
- 163. The form will also serve to:
 - a. review and update any changes to contact permissions i.e. who the person consents to being involved in the process (including both professionals and friends/family)
 - b. review and update any personal details for example if the person has moved from their home to hospital
 - c. record any emerging conflicts of interest of any involved professionals and Care Navigators.

Slowing or pausing the process

- 164. After having made a First Formal Request (Step 1) (see paragraph 217), if a person chooses to slow or pause the assisted dying process at any point and indicates this to any involved professionals or the Care Navigator, this will be recorded in their Assisted Dying Person Record (see paragraph 177), including any associated wishes for example:
 - a. If choosing to slow the process,, the person can, for example, request the Jersey Assisted Dying Service to contact them on a particular date in the future (e.g., in 2 weeks' time)

b. If choosing to pause the process the person can, for example, request that the service does not contact them and they will contact the service if and when they wish to resume the process.

Withdrawal of request

- 165. The person may choose to fully withdraw their request for an assisted death at any point in the process prior to administration of the assisted dying substance at Step 7, including after approval has been given and / or confirmed by a tribunal.
- 166. The process ends as soon as the person withdraws their request.
- 167. The person may withdraw verbally or by any other appropriate means of communication to any involved professional or the Care Navigator.
- 168. The involved professional must immediately alert the Coordinating Doctor (if the Coordinating Doctor is not the involved professional who was informed) who must then:
 - a. speak with the person to confirm their withdrawal request
 - b. complete and sign a withdrawal of request form (the details of which will be prescribed by Order of the Minister)
 - c. confirm the withdrawal of request to the person, in writing
 - d. make arrangements for the Tribunal, if relevant, to be informed of the withdrawal
 - e. inform other attending practitioners or carers, who were previously informed of the request, of the subsequent withdrawal. They must have the consent of the person to inform the other attending practitioners or carers.
 - f. inform family members, friends and other third parties of the subsequent withdrawal, where they have been involved in the process to date. They must have the consent of the person to inform family members, friends and other third parties.
- 169. It is understood that the person may tell other attending practitioners or carers or a family member, as opposed to an involved professional or the Care Navigator, of their wish to withdraw their request. To help assist in this eventuality, the Guidance for Families and Carers, published by the Assurance and Delivery Committee will set out how to notify the Jersey Assisted Dying Service of the wish to withdraw.
- 170. The completed withdrawal of request form must be retained by the Jersey Assisted Dying Service in line with the retention schedule for regulatory,

oversight and reporting purposes. The assisted dying service must report to the JCC, on an annual basis:

- a. the numbers of withdrawal of requests
- b. the stage of the application/delivery process when the request was withdrawn.
- 171. A person who has withdrawn their request may, at any later date, start the request processes again from the beginning (i.e., they will need to go back to Step 1 and make a first formal request) but the fact that they had previously withdrawn a request must be considered by the assessing doctors when determining whether their wish for an assisted death is clear and settled.

Minimum timeframes

- 172. The law will set out minimum timeframes for the assisted dying process. Where a person meets the 'Route 1 terminal illness' criteria the minimum timeframe is 14 days subject to the exception described in paragraph 174, below. Where a person meets the 'Route 2 unbearable suffering' criteria the minimum timeframe is 90 days.
- 173. The timeframe will, in both cases, be from the date on which the person makes their first formal request (Step 1) for an assisted death, to the date on which they are assisted to end their life (Step 7).
- 174. The statutory minimum timeframes will help to ensure that the person who has requested an assisted death has had time to reflect on their decision i.e., help safeguard against hasty decision making or fluctuating wishes for an assisted death:
 - 14-day minimum timeframe is proposed for 'Route 1 terminal illness', on the basis that 14 days allows sufficient time for all assessments to be completed, and time for the assessing doctors to be confident that the request for an assisted death is enduring, whilst not unduly extending any suffering and uncertainty for the person. This is in line with legislation in the US, Spain, Austria and the proposals set in the Isle of Man Assisted Dying Bill and Scottish consultation proposals.
 - The law will also provide that this minimum timeframe may be shortened if, in the opinion of both the Coordinating Doctor and the Independent Assessment Doctor, the patient is likely to die in less than 14 days from the date on which the person made their first formal request. In the cases there will be no minimum timeframe (this includes the removal of the 2 working days period between the final approval and the administration of the assisted dying substance [see section 8: Appeals]) but all other processes of the assessment and approval process must be undertaken as set out in these proposals including, for example, any additional assessments. Some other

- jurisdictions including Western Australia allow for shortened minimum timeframes in the event that a person is expected to die within that time.
- a 90-day minimum timeframe is proposed for 'Route 2 unbearable suffering' due to the gravity of the decision made a person who meets 'Route 2 unbearable suffering' criteria does not have a terminal illness, therefore the end of their life is not imminent. A decision to end their life through assisted dying is altering the trajectory of their life in a way that is fundamentally different from a person who has a terminal illness. The 90-day assessment period allows time for additional assessments and opinions to be sought and confirmation that the request is enduring, as well as time to ensure that all other options for the person have been explored in terms of treatment, pain relief and the provision of any other services that may be able to alleviate the person's suffering. This is in line with legislation in Canada and Austria.
- 175. There will be no maximum timeframe set out in law on the grounds that;
 - a. the person must be able to dictate the pace at which they move through the process (beyond the minimum timeframes); and
 - b. in some cases, there will be a requirement to involve specialist professionals and access to those professionals may be limited.
- 176. The Minister will, however, publish the services standards including target maximum timeframes for the Jersey Assisted Dying Service, as developed by the Committee.

Assisted dying forms and Assisted Dying Person Record

- 177. At each Step in the process there will be forms to be completed by the assessing doctors, Administering Practitioner and others [see appendix 3 Forms and guidance]:
 - a. the forms will be in such a form as the Committee decides (i.e., electronic, paper etc.) and will include the information / particulars prescribed by the Minister by Order
 - b. all completed forms will be retained in accordance with the retention schedule and included in the Assisted Dying Person Record
 - c. all completed forms will be subject to a post-death administrative review following the provision of an assisted death and available for review, on request, by the Jersey Care Commission as part of their inspection process.
- 178. An Assisted Dying Person Record will be created for every person who makes a First Formal Request. This is a single record detailing all information about a person's request, assessment, approval, planning and delivery of an assisted death, including all forms.

- 179. The Assisted Dying Person Record will be an electronic record, that may be held separately to a person's hospital record. The Committee will develop Assisted Dying Person Record Guidance to clarify the use of, and access to the record, for example that the record may only be accessed by the involved professionals and Care Navigator and any other person who has authority to do so, for example the Assisted Dying Review Panel.
- 180. The Assisted Dying Person Record will also be subject to audit by the Jersey Care Commission as part of their inspection services and all forms will be provided in full to the Assisted Dying Review Panel as part of the post-death administrative review.
- 181. Details of an assisted dying practitioner's current and past case load and involvement with assisted dying requests will be recorded in the Assisted Dying Person Record system, separately from the individual person, and will be available for inspection and monitoring processes by the Jersey Care Commission and the Assisted Dying Review Panel. [See section 10 Regulation and oversight]
- 182. The Assisted Dying Person Record will be a real-time single point of data where all relevant information on a person's request, assessment, approval, planning and provision of an assisted death is held. This includes:
 - a. Contact information for the person, including preferred method of contact and preferred form of address
 - b. Referral documentation
 - c. First Formal Request form
 - d. All Declaration of Interest forms signed by the involved professionals and the Care Navigator
 - e. All Step Transition forms and Doctor Transfer forms
 - f. First Assessment Report form
 - g. Independent Assessment Report form
 - h. Any Second Opinion Assessment Report forms
 - i. Second Formal Request form
 - j. Administrative Review (approve or decline) form
 - k. Record of approval or decline by Tribunal [Route 2 only]
 - 1. Record of any appeals

- m. Any other supporting or relevant documentation, including additional assessments or advice and opinions that formed part of either the first, independent or second opinion assessments.
- n. Final Consent and Review form
- o. Post-Assisted Death Administration form

Interpreting, communication support and advocacy

- 183. When a person is referred to the Jersey Assisted Dying Service, the Care Navigator will work to determine whether the person needs any additional support or interpreting provision. This may include:
 - a. foreign language / British Sign Language interpreters this may involve inperson or remote interpreting support via video link
 - b. communication support this could involve technology such as speech to text software, or in-person support from a professional such as a speech and language therapist
 - c. independent advocacy this involves support for the person to get the information they need to make choices about their current care and treatment options and request for assisted dying. And to support the person to put their choices across to professionals during the assisted dying process.³³
- 184. This support will be arranged by the Jersey Assisted Dying Service. The provider may work for HCS or may be an external provider.
- 185. Guidance will be produced by the Committee, it will specify:
 - a. the process for arranging for interpretation, communication or advocacy support, which will be the responsibility of the Jersey Assisted Dying service
 - b. that a person with a disability, where that disability affects their ability to communicate, can use their preferred means of communication (e.g. a communication aid, writing or gestures) during the assessment process
 - c. where remote support / interpreting is appropriate and which stages of the process require in-person support
 - d. support available to the professional providing the communication support, if required

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³³ Someone to speak up for you (advocate) - Social care and support guide - NHS (www.nhs.uk)

- e. additional considerations for the assessment process, for example:
 - the assessing doctor should allow for additional time for the consultation, if support or advocacy is required
 - potential requirement for pre-brief and debrief with the interpreter or communication support, to allow for a shared understanding of the process and purpose of the session and to discuss any sensitive matters.
- 186. The law will set out that the provider of the communication support, advocacy or interpreting will need to sign a declaration confirming:
 - a. they are not a family member or personally connect to the person
 - b. they will not benefit financially or in any other material way from the death of the person
 - c. detail of any previous health or professional care they are or have been providing to the person
 - d. detail of the providers professional qualifications, role and the organisation they currently work for
 - e. With regard to interpreters, whether or not they hold a nationally recognised interpretation qualification and are registered with the NRPSI (National Register of Public Service Interpreters) or equivalent body.
- 187. The provider will also be required in law to sign the relevant assessment report forms. For example, if the provider provided support during the First Assessment:
 - a. a description of their involvement will need to be captured on the First Assessment Report form
 - b. they will need to sign the First Assessment Report form to confirm the accuracy of the description of their involvement.

Remote consultations

188. Assessment Guidance will set out that assisted dying consultations should, as a matter of course, be in-person meetings. They may take place in the person's home, place of care or elsewhere such as the Jersey General Hospital. There may be certain circumstances where follow-up consultation can be carried out remotely i.e. over the phone, via video link or online (for example, clarification of matters already discussed) but initial and in-depth consultation should be inperson. The guidance will set out the circumstances where this may be appropriate.

189. All consultations (whether in-person or remote) must be conducted on-island. If the assisted dying practitioner is a non-Jersey based professional, they must travel to Jersey to undertake the consultation. This is to ensure there are no difficulties with a practitioner supporting assisted dying in a jurisdiction where assisted dying is not legal. Currently, assisted dying is not permitted in the UK and it is an offence to actively encourage or assist someone with ending their life. NOTE: this does not apply to professionals who are providing supporting assessments or opinions only, as they are not making any determination of eligibility for assisted dying [see section Supporting opinions / assessments from other professionals].

Involvement and support for family and loved ones

- 190. The person requesting assisted dying will be encouraged to involve family and loved ones in the process unless there are specific reasons not to do so.
- 191. However, the person has a right to privacy and will not be required to inform family members about their request, assessment, or approval for assisted dying. Nor will they be required to provide consent for any the Jersey Assisted Dying Service to contact family members.
- 192. If the person chooses not to involve family members, the Coordinating Doctor will inform them that this may have an impact on their ability to assess them as eligible. For example, without speaking to the family, the assessing doctor may not be able to determine if the person is requesting assisted dying voluntarily and without coercion.
- 193. Where the person does consent to family members being involved in the process, the Care Navigator and Coordinating Doctor will work with the family members to support them through the process, alongside the person requesting assisted dying. This will involve making themselves available to the family members for discussions about the process and answering any questions. It may also involve signposting them to other support and wellbeing services provided by HCS or other providers.
- 194. If a family member does not support the person's request for assisted dying, this will not affect the assessment of the person's eligibility (i.e., a person would not be ineligible on the basis that their family do not support their wishes), unless the family member's lack of support is based on a belief that the person does not meet the eligibility criteria, and the Coordinating Doctor agrees with them (for example, they believe they are not making the request voluntarily).
- 195. For family and loved ones of those who do go on to have an assisted death, this support will continue after the death, including referral to be reavement support services. Based on the experience of other jurisdictions, be reaved families who have experienced an assisted death may wish to be supported to meet together to share their experiences and the Jersey Assisted Dying Service would look to facilitate this, taking into consideration wishes for privacy and or anonymity in a small island community.

- 196. The Committee will publish Guidance for Families and Carers, which will include easy to understand information on:
 - a. their role in the process
 - b. the appeals process
 - c. how to support a family member who is requesting assisted dying
 - d. how to access support services
 - e. how to notify the Jersey Assisted Dying Service, if a loved one indicates they wish to withdraw their request

Declaration of Interest form

- 197. All assisted dying practitioners will be required to complete an annual Declaration of Interest form, prescribed by Order by the Minister, which details any:
 - a. directorship, partnerships or registerable share holdings
 - b. membership of governing bodies or other public bodies
 - c. interests related to assisted dying or end-of-life care including those related to previous current employment or consultancy
 - d. interests of close family members
 - e. other matters which may be perceived to create a conflict
- 198. This information will be held as part of their registration with the Jersey Assisted Dying Service.
- 199. In addition, all involved professionals (except Pharmacy Professionals) and the Care Navigator will be required to complete a 'Part B' of the Declaration of Interest Form for each person requesting assisted dying, declaring whether they:
 - a. are a relative of the person
 - b. a friend or associate of the person, including a description of the capacity in which they know them
 - c. are a known or potential beneficiary of the person's Will
 - d. may otherwise benefit financially or in any other material way from the death of this person

- e. are the owner, provider or manager of a health or care facility where the person is being treated or lives
- f. are directly involved in providing health or care to the person and if so, in what capacity or role
- g. have any other interests or potential conflicts.
- 200. The Declaration of Interest form will be risk assessed by the HCS Medical Director if any interests are declared which potentially represent a conflict of interest.

Section 7: Assisted dying process - request, assessment and approval

This section details how requests, assessments and approvals for assisted dying will operate (Steps 1 to 5 of the proposed assisted dying process). These are the steps to ensure that only people who meet the eligibility criteria set out in law are approved for an assisted death.

This section also details activity prior to the commencement of formal process steps, for example, referrals and requesting information (known as "pre-process steps").

Pre-process steps: information and referral to the Jersey Assisted Dying Service

- 201. The Jersey Assisted Dying Service will work to ensure people have access to information that supports them to make informed decisions about end-of-life matters. This will include information about assisted dying, palliative care and end-of-life care and related matters, such as care funding and financial planning. This will include:
 - a. a dedicated website
 - b. a telephone and email advice line
 - c. information leaflets for members of public
 - d. advice, guidance and training for all professionals on matters such as:
 - speaking with persons / clients about assisted dying
 - referring persons / clients who are considering an assisted death
 - opting in as an assisted dying practitioner.

This includes the guidance that the Minister is required by law to issue (including Conscientious Objection Guidance and Appropriate Conversations Guidance).

- 202. The service will provide information about assisted dying and will also support people to access information and support on other end-of-life matters through signposting or referral to other providers.
- 203. The assisted dying information will be available in accessible formats, including other languages, formats accessible to those with sight and hearing impairments, and easy read. The service will work with other providers, for example, GPs to ensure they have information 'on hand' to provide to patients who have asked about assisted dying.

General enquiry

- 204. A person who wants more information about the Jersey Assisted Dying Service may make direct contact with the Service (via phone, email or an online form).
- 205. Basic details of all general enquiries will be logged by the Jersey Assisted Dying Service for annual reporting purposes (i.e., number and type of inquiries) but the names of people making inquiries will not be recorded other than where the person has specifically provided their name for the purpose of ongoing contact and discussion. This is to ensure that people feel able to make confidential private initial inquiries.

Self-referral

- 206. A person who is potentially considering making a request for an assisted death may directly contact the Service about requesting an assisted death (this is called self-referral) or they may be referred by another professional, for example, their GP (this is called professional referral) but professional referral into the service is not a requirement, unlike for many other services.
- 207. When a person self-refers to the Service, initial contact will be with a Care Navigator. A person may wish to have several informal discussions with the Care Navigator over a period of time before deciding to make a first formal request for assisted dying (or deciding not to make a first formal request)
- 208. If a person tells the Care Navigator they want to make a first formal request for assisted dying, the Care Navigator will:
 - a. arrange for the person to meet with a Coordinating Doctor so that they can begin Step 1: first formal request [see paragraph 217]
 - b. set up an assisted dying record for that person and formally record that fact a meeting has been arranged with a Coordinating Doctor in that record [see paragraph 177]
 - c. establish if the person requires any interpreting or communication support, record this requirement in their assisted dying record and put the required support in place ahead of their meeting with the Coordinating Doctor [see paragraph 183].
- 209. The person who is making a self-referral, or is being referred by a professional may, or may not, have already made general enquires of the Service.

Professional referral

210. If a health and care professional has a conscientious objection to assisted dying, they will not be required to refer the person to the Jersey Assisted Dying Service, but they will be expected to provide contact information for the Jersey

Assisted Dying Service to the person, so that the person can make a self-referral or make arrangements for another professional to make a referral [see paragraph 98].

- 211. When referring a person to the Jersey Assisted Dying Service the health and care professional will be required to complete an Initial Enquiry form, this form will detail:
 - a. Basic person information (name, address etc.)
 - b. Details of the referrer (including professional relationship to person e.g., their GP)
 - c. Nature of the referral request (e.g., further information about assisted dying or a formal request for assisted dying)
 - d. Date of discussion and date when the form is sent to Jersey Assisted Dying Service
 - e. Any other relevant information
- 212. If the professional referral is a request for information, the Care Navigator will contact the person in the first instance.
- 213. If the practitioner referral is to make a first formal request for assisted dying, the Care Navigator will:
 - a. arrange for the person to meet with a Coordinating Doctor so that they can begin Step 1: first formal request [see paragraph 217]
 - b. set up an assisted dying record for that person and formally record the fact that a meeting has been arranged with a Coordinating Doctor in the person's record [see paragraph 177]
 - c. establish if the person requires any interpreting or communication support, will record this requirement in their assisted dying record and will put the required support in place ahead of their meeting with the Coordinating Doctor [see paragraph 183].
- 214. All professional referrals will be logged by the Jersey Assisted Dying Service, this record will include details of all follow-up contact with the person who has been referred. If the person goes on to make a first formal request, this information will be included on the person's assisted dying record [see paragraph 177].
- 215. Details of self-referrals and professional referrals will be held confidentially and be retained by the Jersey Assisted Dying Service in line with the retention schedule for regulatory, oversight and reporting purposes. Numbers of referrals received by the Jersey Assisted Dying Service will be reported on anonymously in the Assisted Dying in Jersey annual report [see paragraph 85]

216. In order for a person to have a lawful assisted death, the law will set out that a person must make a first formal request for an assisted death, have a first assessment and independent assessment, then make a second formal request for assisted dying. The Coordinating Doctor will then carry out an administrative review of the requests and assessments and either approve or decline the request for assisted dying, on the grounds that the person does or does not meet all the eligibility criteria set out in law. If the person is eligible under 'Route 2 – unbearable suffering', the Coordinating Doctor's approval must then be confirmed by a Tribunal.

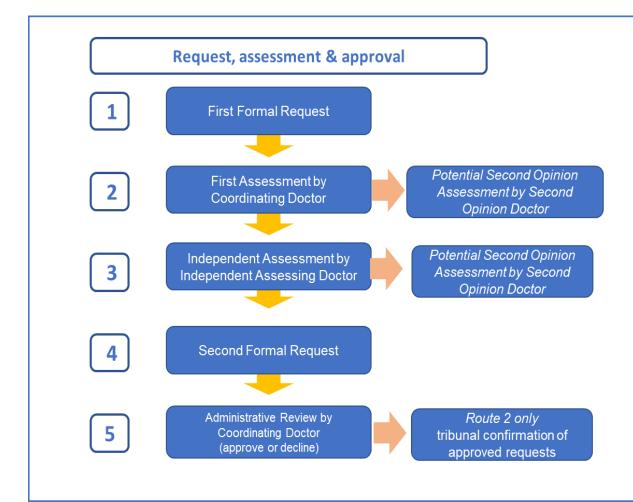


Figure 2 - process steps for request, assessment and approval for assisted dying

Step 1: First formal request

First Formal Request meetings and form

217. The first formal request 'starts' the assisted dying process and signifies a shift from informal consideration of assisted dying to formal intent of a person to initiate the assisted death assessment process.

- 218. It is a process which involves the person discussing their prognosis, treatment options and assisted dying with the Coordinating Doctor and culminates in them determining if they want to make a first formal request for an assisted death. This may require only one first formal request meeting or may take place over several meetings and discussions, and potentially over a protracted period of time.
- 219. The law will provide that if the person decides to make a first formal request, that request must be clear and unambiguous. It must be made in writing, using a First Formal Request form.
- 220. If the person making the request is physically unable to sign a written form, they may instruct someone sign on their behalf but <u>only</u> if they are physically unable to do so (i.e., there are no other circumstances in which the request form can be signed by another person).
- 221. The person signing on their behalf ("the signatory") may be any person aged 18 or over who is not the Coordinating Doctor, any other involved professional or the Care Navigator. It can be a friend or family member of the person because, in this event, they are only signing to acknowledge that the person has made a request, at the request of the person.
- 222. The First Formal Request form must be signed and dated by the Coordinating Doctor and the person or their signatory, at the same time, and in the presence of each other. Note: at the stage at which the second formal request is signed, there is an additional requirement for that second form to be signed by a witness in addition to any signatory. [See paragraph 339]
- 223. The First Formal Request form will be prescribed by Order by the Minister and will include:
 - a. times and dates of all Formal First Request meetings including details of who was present at each meeting
 - b. a summary of what was discussed at all meetings including a record of the information provided to the person (sufficient information must be provided by the Coordinating Doctor to ensure that person is properly and fully informed of the assisted dying assessment process before making a First Formal Request)
 - c. detail of communication or advocacy support provided during the meetings or identified as being required in all further stages of the assessment process
 - d. the Coordinating Doctor's declaration that they are eligible to act in the capacity of Coordinating Doctor for this person
 - e. details of the signatory, where relevant (name, contact details, relationship to the person)

- f. details of consents requested and provided, and confirmation that person has been informed of the potential implications of providing or not providing consent (see note below)
- g. the person's declaration that they are requesting an assisted death e.g., I declare that I am requesting an assisted death and that I make this request voluntarily and without coercion.

Note: Consents

The first formal request form will include details of all consents requested by the Coordinating Doctor and whether or not the person provides those consents.

This will include whether or not the person has provided consent to the Coordinating Doctor and / or others (for example: any assessing doctor and / or any member of the MDT and / or Care Navigator) to allow:

- i. accessing the person's medical records
- ii. informing and / or sharing information with and / or seeking information from other persons as part of assessment process. This may include:
 - other attending practitioners and carers that are providing care and treatment to the person, whether named professional (for example the person's Consultant or GP) or unnamed professionals, for example the care staff at their residential home or on a hospital ward
 - other relevant professionals who may be asked to provide independent opinion or undertake an independent assessment
 - any other people the person wishes to be part, or informed of, the assisted death process, including but not limited to family members
- iii. seek information from any relevant Government of Jersey department in order that the department may provide supporting information that enables the Jersey Assisted Dying Service to confirm residential status and age (as two of the assisted dying eligibility criteria). This will not include disclosure of the person's assisted dying request as it is not relevant to the information being sought.

Where the person chooses not to provide the consent requested, the Coordinating Doctor or other assessing doctors may be unable to confirm eligibility for an assisted death (as they may, for example, be unable to determine the voluntary and settled nature of the wish without third party input).

The person must be informed as part of the first formal request of the potential implications of not providing consents (as set out above) and of providing consents (i.e., people will know about the request and may attempt intervention if they are not supportive)

It may be necessary at any point during the assessment process for the Coordinating Doctor or any other assessing doctor to seek additional consents from the person. All requests for additional consents must be recorded on the person's assisted dying record, including whether the person does or does not provide that consent, and who the person provides the consent to (i.e., Coordinating Doctor only and / or others).

- 224. A complete and signed copy of the first formal request form must be included in the person's assisted dying record.
- 225. The law will provide that a person whose request for an assisted death has not been approved, as a result of a determination that the person is not eligible following assessment, may then make another first formal request on the grounds that their circumstances have changed. However, a Coordinating Doctor has the right to refuse this new first formal request, unless the Coordinating Doctor believes the changes to the person's circumstances are such that they may now be eligible for an assisted death. The Coordinating Doctor may make this decision following a review of the person's previous Assisted Dying Person Record and any current medical notes or care record.

Note: The request

The Assisted Dying process requires a first formal request at Step 1 and a second formal request at Step 4. For the purposes of clarity this is a single request for an assisted death which the person makes on two occasions.

Residency

- 226. The proof of residency check will be undertaken by the HCS team that currently deals with eligibility matters for accessing other HCS services, working with the Care Navigator as soon as the person provides the necessary consent during a first formal request meeting and prior to the First Assessment meeting.
- 227. Where it is found that the person does not meet the criteria on grounds of residency, they will not be able to proceed to a first assessment (Step 2) and cannot make a further first request (Step 1) until they have been ordinarily resident for at least 12 months.
- 228. Where a person contests that they meet the residency criteria (i.e., they claim they have been resident in Jersey for 12 months or more) despite being initially assessed as not meeting those criteria, the HCS team will undertake further proof of residency checks. If the person is then found to meet the residency criteria, they may proceed to a first assessment (Step 2). If they are still not found to meet the residency criteria but claim that they do they may appeal to the Court (see appeals).

<u>Age</u>

- 229. If a proof of age check is required (in most cases it will not as it will be self-evident that a person requesting assisted dying is aged 18 or over):
 - a. The person will be asked as part of the first formal request meeting to provide consent to the Assisted Dying Service seeking information from any relevant GOJ Department in order that the Department may confirmation of age, or

- b. In the event that information is not available, the law will provide that Coordinating Doctor may ask the person for proof of age in the form of photographic ID such as a passport or driving licence
- 230. Where it is found that the person does not meet the criteria on grounds of age, they cannot proceed to a first assessment (Step 2) and they cannot make a further first request until they are aged 18 or over.
- 231. The law will provide that:
 - any relevant Government of Jersey department may share information surrounding age or proof of residential status with the Jersey Assisted Dying Service
 - b. the Coordinating Doctor has a duty to confirm they are satisfied that the residency and age criteria have been met.

Step 2: First assessment

- 232. Detailed Assessment Guidance on carrying out a First Assessment will be developed by the Committee. The First Assessment Report form will be prescribed by Order by the Minister. The First Assessment Report form will form part of the person's Assisted Dying Person Record.
- 233. A first assessment will be undertaken by the Coordinating Doctor, supported by the multidisciplinary assisted dying team (the MDT). The first assessment is necessarily a thorough process. In some limited cases it may require only one assessment meeting, but it is likely to require more than one meeting with the person. Furthermore, the Coordinating Doctor may require additional assessments or opinions in order to determine whether or not the person meets the eligibility criteria.
- 234. Before the first assessment begins the person must confirm to the Coordinating Doctor or Care Navigator that they wish for the first assessment to be undertaken, which will be recorded on the Step Transition form (see paragraph 161).
- 235. The Step Transition form may only be completed once the completed and signed First Formal Request form has been entered into the person's assisted dying record.
- 236. The first assessment may take place immediately after the first formal request or at a later date, depending on the wishes of the person.
- 237. The Coordinating Doctor will make a final determination of eligibility following the first assessment, but this may involve:

- a. meetings with the MDT to discuss the case and provide professional check and challenge [for further information see *Assisted Dying Multidisciplinary Team* after paragraph 322], and / or
- b. the Coordinating Doctor seeking opinion or additional assessment from a relevant professional outside of the Jersey Assisted Dying Service information [see *Supporting opinions / assessments from other professionals* after paragraph 322], and / or
- discussion with other relevant third parties such as family members or friends.
- 238. The purpose of the first assessment is for the Coordinating Doctor to determine if the person meets the eligibility criteria in law (age and residency-status will be pre-assessed). By the end of the first assessment, they must determine if the person:
 - i. is aged 18 or over
 - ii. has been ordinarily resident in Jersey for at least 12 months
 - iii. meets all the health eligibility criteria for either Route 1 or Route 2
 - iv. has a voluntary, clear, settled and informed wish to end their own life, which includes being satisfied that the request is made in absence of any undue pressure or coercion by any other person
 - v. has decision-making capacity in respect of their assisted dying request
- 239. The first assessment process must fully explore with the person their request for an assisted death and the fears, anxieties and suffering that gives rise to that request as well as their understanding of the impact of requesting and having an assisted death.
 - i. age & ii residency
- As set out in paragraphs 226 to 231 above, the age and residency checks will have been completed before commencement of the first assessment stage, but the law will require that the Coordinating Doctor has a duty to confirm on the First Assessment form they are satisfied that the required age and residency criteria have been met.
 - iii. health eligibility criteria
- 241. Diagnosis and prognosis of a terminal physical medical condition (Route 1) or an incurable physical condition (Route 2)
- 242. The Coordinating Doctor will need to determine whether the person meets the:

- a. the health eligibility criteria under 'Route 1 terminal illness' or
- b. the health eligibility criteria under 'Route 2 unbearable suffering' or
- c. does not meet either criterion.
- 243. In order to make this determination the Coordinating Doctor will review the person's medical records (if consent had been obtained) and consider their medical history and prognosis.
- 244. In order to be assessed as eligible under 'Route 1 terminal illness', the person must have an incurable physical medical condition that is reasonably expected to cause the person's death within 6 months or less, or within 12 months in the case of a terminal neurodegenerative condition. As set out in paragraphs 34 38, it is acknowledged that doctors cannot be exact when predicting an individual's life expectancy, therefore the law will provide that doctors may make an assessment of expectancy which they determine is reasonable based on their medical knowledge and their examination / assessment of each individual person.
- 245. If the Coordinating Doctor is of the opinion that the person is eligible under Route 1 and has a life expectancy of less than 14 days from the date of their first formal request, this must be recorded on the First Assessment Form and the Independent Assessment Doctor must be notified of this.
- 246. If the Coordinating Doctor is unable to make a determination on the basis of medical records alone, the Coordinating Doctor must seek further opinion or assessment from another relevant professional, with the person's consent, which may be the person's consulting practitioner or a consultant who has expertise in the person's medical condition [see *Supporting opinions / assessments from other professionals* after paragraph 322]. For example, if the person has terminal cancer, the Coordinating Doctor may need speak with the treating oncologist, or an independent oncology expert, to confirm that the person has a life expectancy of 6 months or less.
- 247. The relevant professional may be asked by the Coordinating Doctor to:
 - a. undertake an assessment of the person, including potentially conducting any relevant tests or examinations
 - b. review the person's medical notes and / or treatment and care plan
 - c. provide generic professional advice and opinion
 - d. undertake any other clinically appropriate investigation.

Suffering

- 248. In order to be eligible for an assisted death, the person will need to have a physical medical condition which is giving rise to unbearable suffering (or, applicable under Route 1 only, is expected to give rise to unbearable suffering) that cannot be alleviated in a manner the person deems to be tolerable.
- 249. The law will therefore provide that the assessing doctors must determine that:
 - a. there is suffering (whether physical and / or mental) OR that suffering is expected to arise, and
 - b. the cause of that suffering / expected suffering is the physical medical condition, and
 - c. the suffering / expected suffering cannot be alleviated in a manner the person deems to be tolerable.
- 250. The assessments related to suffering will apply to both Route 1 and Route 2, the assessment of expected suffering will apply to Route 1 only.
- 251. The law will not require the assessing doctor to determine whether the suffering is unbearable as this is entirely subjective (see below). It will require the assessing doctor to be satisfied, to their best of their ability, that the person's own determination that they cannot bear their suffering / will not be able to bear the anticipated suffering, is, like their request for an assisted death, voluntary, clear, settled and informed.

Presence and cause of suffering

- 252. The law will state that the person's suffering must be caused by their physical medical condition for both Route 1 and Route 2. It will define suffering as including:
 - a. physical suffering (for example, pain) and / or
 - b. mental suffering (for example, anguish associated with inability to carry out daily tasks or communicate due to the person's physical medical condition), and /or
 - c. suffering caused by the treatment provided for the physical medical condition.
- 253. The assessing doctors must determine that either:
 - a. there is suffering (whether that is physical and / or mental suffering)
 - b. there is an expectation of suffering (Route 1 only).
- 254. They will make this determination based on their assessment of the person (and any supporting assessments) and their knowledge of the physical medical

condition and its likely impact on people. Key to this determination will be consideration of whether the person is suffering / likely to suffer or whether their claim of current suffering / stated fear of expected suffering arises from coercion. It must be the person who is articulating their suffering as opposed to any third-party articulating suffering / fear of suffering on their behalf (although the assessing doctors may seek opinion from third parties as required). [Note, this does not exclude the use of interpreters or communication support by the person to communicate.]

- 255. In most cases suffering or fear of expected suffering will be self-evident.
- 256. Having determined that there is suffering / expectation of suffering the assessing doctors must then determine whether that suffering arises from the person's physical medical condition.
- 257. Suffering arising solely from the following will not satisfy the requirements under law even where the person has a physical medical condition (including where the condition is terminal under Route 1) because the suffering does not arise from the physical condition:
 - a. the person's living situation (for example, their relationship has just broken down)
 - b. generalised fears about the future (for example, concern about debt)
 - c. generally 'being tired of life'.

258. Causes of suffering may include:

a. the physical medical condition itself and the impact of that physical medical condition

A person has terminal lung cancer (their death is anticipated in 4 months). They are experiencing extreme discomfort and severe physical pain. The person would be eligible under Route 1 because they have a terminal physical medical condition, and their physical suffering arises directly from that condition.

5 years ago, a person was involved in a serious motor vehicle accident. As a result, they suffered life-changing injuries, including paralysis from the neck down and chronic pain. The person requires 24-hour care support. The person has unbearable suffering caused by their chronic pain, the inability to carry out basic day-to-day tasks, difficulty speaking, loss of bodily functions and inability to feed themselves, but their death is not reasonably anticipated.

The person would be eligible under Route 2 because they have a physical medical condition(s) and their mental suffering / anguish arises from that impact that the physical condition is having on their life.

b. the treatment provided for the physical medical condition

A person with stage IV breast cancer is experiencing significant side effects from chemotherapy including severe fatigue, nausea and vomiting and repeated infections, all of which cause suffering, alongside an expectation of further physical suffering close to the end of their life due to the progression of the cancer. With a life expectancy of less than 2 months

The person would be eligible under Route 1

c. complications of the person's treatment for their physical medical condition

A person received has chemotherapy treatment for leukaemia. A significant long-term side effect of the chemotherapy was chronic heart failure. The heart failure is giving rise to shortness of breath and exhaustion, as well as severe pain and in inability to walk or leave the house, all of which contributed to the person's physical and mental suffering.

The person would be eligible (potentially under Route 1 or Route 2 depending on the prognosis associated with the heart failure)

- 259. Current mental suffering that is arising (as opposed to mental suffering that could potentially arise in the future) from the following may satisfy the requirement under law in the absence of physical suffering where the person has a physical condition, and the assessing doctor determines that mental suffering arises from that condition:
 - a. a desire to relieve distress over a loss of autonomy (for example, inability to undertake day-to-day tasks such as toileting)
 - b. fears about their pending death / the suffering associated with that pending death
 - c. desire to control the circumstance around their death
 - d. fears about the burden on loved ones.
- 260. Suffering that arises from mental illness alone will not satisfy the conditions of the law, but a person with a mental illness may be eligible for an assisted death if they also have physical medical condition which is giving rise to suffering.
- 261. The presence of mental illness (such as depression) is not uncommon in people at end of life. The Coordinating Doctor will need to determine if any mental anguish or suffering a person is experiencing arises from:
 - a. mental illness alone
 - b. a combination of their mental illness and physical condition.

262. Where there is uncertainty as to the cause of mental suffering, the Coordinating Doctor must make a referral for determination to a relevant professional with training and skills to support determination of the matter. This may include a psychiatrist or psychologist.

Person A

Person A has a diagnosis of Schizophrenia. This is causing them to experience mental anguish and suffering. However, they <u>would not be eligible for assisted</u> dying under Route 2 as they do not have a diagnosis of a physical medical condition.

Person B

Person B has a diagnosis of advanced prostate cancer, with a life expectancy of over 5 years. This is a physical medical condition, so the person *may* be eligible under Route 2 – unbearable suffering. Person B also has a diagnosis of post-traumatic stress disorder (PTSD), which is a mental illness. The person states they are experiencing unbearable suffering. During their assessment the Coordinating Doctor determines that their suffering is exclusively as a result of their PTSD and the impact this has on their day-to-day life, and that their prostate cancer is not advanced and is not causing any suffering from physical pain or from fears around the end of their life. As a result, the person would not be eligible for assisted dying.

Person C

Person C has been diagnosed with end-stage chronic obstructive pulmonary disease (COPD) (a physical medical condition) with a life expectancy of 3 months; they also have a diagnosis of depression.

Person C's request for assisted dying would be approved. They <u>would be eligible</u> <u>under Route 1</u> as they have a terminal diagnosis and have demonstrated to the Coordinating Doctor that their unbearable suffering is, at least in part, a result of their COPD as they can no longer carry out basic day-to-day tasks, have difficulty speaking, and feel anguish about being a burden to others.

Is the suffering bearable?

- As set out above, the law will provide that the assessing doctors must determine that there is suffering / expected suffering (whether physical and / or mental) and they must determine the cause of that suffering / expected suffering but the law will not require them to determine if the suffering / expected suffering is unbearable.
- 264. Suffering is a subjective experience, as is fear of anticipated suffering. Different people experience suffering or fear of suffering in different ways, and hence it is only the person who can determine what that person believes they can bear.
- 265. The law will require the assessing doctors to:

- a. document the person's own determination of whether they can bear their current suffering or the expected suffering, and
- b. be satisfied, to their best of their ability, that the person's own determination is a voluntary, clear, settled and informed determination (i.e., it is free from coercion).
- 266. As part of this, the assessing doctors will need to be satisfied that the person understands that:
 - suffering is not fixed, the physical pain and the mental, emotional, social, spiritual or existential anxiety and suffering associated with an incurable physical medical condition may fluctuate
 - b. a person's ability to tolerate suffering may be impacted by life events or circumstances, for example:
 - the emotional joy associated with the birth of a grandchild may make the suffering more tolerable for a period of time
 - the fear of disease progression and deteriorating quality of life may be greater than current quality of life
 - c. fear of expected suffering may be worse than the actual suffering (the physical pain may be more bearable than envisaged; the mental anguish associated with fear of loss of autonomy may be worse than the loss of autonomy).
- 267. Where the person is being assessed under 'Route 1 terminal illness', and they are not currently experiencing unbearable suffering but the physical condition is expected to give rise to suffering, it is clearly the case that the assessing doctors cannot determine if the person can bear future suffering (unlike current suffering which they can often directly witness) hence they can only be satisfied that the person's determination of their own ability to bear future suffering is a voluntary, clear, settled and informed determination.
- 268. It must be recognised that the ability of a person to bear suffering may be multifactorial, arising from:
 - a. a combination of physical and mental suffering, or
 - b. it may be that suffering arising from a longer term physical medical condition, which the person has found to be bearable to date, is compounded by other physical medical conditions and the associated treatment, example below:

A person had a stroke five years ago which left them with paralysis on one side of their body. They generally adapted well to life but have subsequently been diagnosed with cancer – the impact of the stroke on the person's ability to move and easily

communicate, combined with the side-effects of their cancer and the associated treatment has led to unbearable suffering.

Key consideration

It is clearly the case that subjective judgements are required as to whether the person can bear their suffering. Where the person has a terminal illness, with limited life expectancy, concerns related to the subjectivity of these judgements are less acute (as the person is reasonably expected to die) but are potentially more acute where the person is not reasonably expected to die - i.e., they are on Route 2, as opposed to Route 1.

This subjectivity of judgement is central to the concerns expressed in the Assisted Dying in Jersey Ethical Review Report about Route 2.³⁴

iv. voluntary, clear, settled and informed wish to end their own life

269. The law will provide that the Coordinating Doctor must determine, to the best of their ability, whether the person has a voluntary, clear, settled and informed wish to end their own life.

voluntary request for assisted dying

- 270. In order to determine that the person's wish for assisted dying is voluntary, the Coordinating Doctor must be satisfied that request is made in absence of any undue pressure or coercion from any other person.
- 271. Determination of a voluntary decision will involve discussions with the person to understand the reasons why they wish to have an assisted death.
- 272. It may also involve discussions:
 - a. with the person's family and friends about how they feel about the person's decision and what they understand to be the person's underlying motivations and wishes, along with observation and assessment of family dynamics. If a person has not provided consent for the Coordinating Doctor to speak with family and loved ones, the Coordinating Doctor must inform the person that this may impact their ability to determine that the person is acting voluntarily and without coercion.
 - b. With other professionals providing care and treatment to the person. These professionals may have specific observations or may have had conversations with the person or their carers, family or friends which may provide useful insights into the motivation behind the person's decision. As above, the Coordinating Doctor must inform the person that lack of consent to speak with professionals may impact the Coordinating Doctor's ability to determine that the person is acting voluntarily and without coercion

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³⁴ Assisted Dying in Jersey Ethical Review Report.pdf (gov.je)

- 273. Indicators of possible coercion that may detected during a consultation with carers, family or friends present could include:
 - a. excessive deferment by the person to their carers, family or friends for answers, reassurance or explanation
 - b. carers, family or friends talking over the person and answering on their behalf
 - c. inconsistencies in the person's answers to questions about their suffering, illness experience or assisted dying in general
 - d. inconsistencies between what the person says in private to the Coordinating Doctor, and what the person says in the presence of others.
- 274. For these reasons, it may be necessary to talk with the person away from others to determine if there is potential coercion. Questions the Coordinating Doctor could ask in their discussion with the person may include:
 - Are you feeling any pressure from others to request assisted dying?
 - Do you have or are there any significant financial concerns?
 - Do you have any concerns about your family after you die?
 - Is there anything we need to know that you don't want your family to know?
 - What about your family/friends (may include partners, spouse, children, parents, siblings)?
 - o Are they aware of your request for assisted dying?
 - o How do they feel about it?
 - o Do they support your decision?
 - Is your GP aware of your request for assisted dying?
 - Does your GP support it?

Further detail for assessing the voluntariness of a person's decision will be provided in the Assessment Guidance.

275. The law will provide that if the Coordinating Doctor is unable to determine that the person is acting voluntarily and without coercion, they must seek the opinion of another professional who the Coordinating Doctor believes has the appropriate skills and training to make such a determination [see *Supporting opinions / assessments from other professionals* after paragraph 322] they may be another member of the assisted dying MDT or a professional outside of the Jersey Assisted Dying Service, for example a social worker or a psychologist.

- 276. If there is a concern that the person may be experiencing family and domestic violence, financial abuse or elder abuse these issues should be discussed with the person. These concerns should also be considered at an MDT meeting [see *Assisted Dying Multidisciplinary Team* after paragraph 322]. The Assessment Guidance will also set out that the Coordinating Doctor must make a referral to the appropriate adult safeguarding team if there are any safeguarding concerns regarding abuse.³⁵
- 277. If the Coordinating Doctor is not satisfied that the person's decision is voluntary and without coercion, the law will set out that they must assess the person as ineligible.

Clear and settled wish for assisted dying

- 278. In order to determine that the person's wish is clear and settled, the Coordinating Doctor must discuss with the person their reasons for requesting an assisted death.
- 279. The purpose of these discussions is for the Coordinating Doctor to understand the person's wishes and why the person thinks accessing assisted dying will address any concerns. The Coordinating Doctor will ask the person how they reached their decision, including what or who may have influenced them.
- 280. If a person is requesting access to assisted dying because they are concerned that they are a burden on their carers or family, their situation should be explored. This may include the Coordinating Doctor requesting that another member of the MDT, for example the social worker, reviews with the person their current care package and explores additional options for supportive care or respite care.
- 281. The Coordinating Doctor should also seek to understand why the person has raised this concern and what they mean by it. Some people may say they feel like they are a burden because they believe or know that their family members are struggling to support them at the end of their life, while others may use this to start a discussion about their struggles with their current situation such as their sense of burden or loss of dignity. Such comments should also raise a 'red flag' to the Coordinating Doctor to explore whether there may be any element of explicit or implicit coercion underlying the person's request for assisted dying [see paragraphs 270-277 above]
- 282. The 14-day or 90-day minimum timeframes set out in the law, provide time for the assessing doctors to determine that the person is consistent and settled in their wish for assisted dying throughout the request and assessment process.
- 283. Further detail for assessing the clear and settled nature of a person's decision will be provided in the Assessment Guidance.

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³⁵ Report A Concern | Jersey Safeguarding Partnership Board

284. If the Coordinating Doctor is not satisfied that the person's decision is clear and settled, the law will set out that they must assess the person as ineligible.

Informed wish for assisted dying

- 285. In order to determine that the person's wish is informed, the Coordinating Doctor must discuss with the person:
 - a. care and treatment options and likely outcome of care and treatment, including options that the person may previously have discounted. The Coordinating Doctor must ensure the person is:
 - informed about counselling services, mental health and disability support services, community services, hospice and palliative care services; and
 - offered consultations with the professionals providing such services or care.

If the person is being assessed under 'Route 2 - unbearable suffering' this part of the assessment is likely to take a significant amount of time and may involve multiple consultations as the Coordinating Doctor must be satisfied that all options and changes to circumstances that could alleviate the person's suffering have been explored with the person. This could include for example, additional mental health support, counselling or physical adaptations to the person's property.

- b. the person's wishes and preferences in relation to the assisted dying process (including any associated risks) including:
 - options to self-administer or have the assisted dying substance administered; and which of these options may be appropriate for the person
 - potential risks of self-administering or being administered the assisted dying substance for the purposes of causing death
 - that the expected outcome of self-administering or being administered the assisted dying substance is death
 - the request and assessment process, including the requirement for
 - o a second formal request signed in the presence of a witness (the person will have already made their first formal request)
 - o them to consent to the relevant information being shared with the Tribunal (if being assessed under Route 2)
 - the location of their assisted death
 - involvement of their friends and family

- the person and / or their family members to consider whether an assisted death may impact their life insurance arrangements and other financial affairs
- whether they wish to provide:
 - o confirmation of consent to proceed and / or
 - o a waiver of final confirmation of consent (Route 1 only) and / or
 - an advanced directive, refusing resuscitation or similar emergency life-saving interventions.
 [see grey box, after paragraph 426]

286. The Coordinating Doctor will:

- a. remind the person of the option to withdraw their request at any point during the process (see paragraph 165), and that they must confirm their wish to proceed at each step (i.e., the pace and progress of the process is driven by the person, not by the Jersey Assisted Dying Service)
- b. inform them of the appeals process
- c. encourage the person to talk to their family and friends about their request
- d. support the person to determine whether they want other attending practitioners and carers to be informed of their wishes.
- 287. The Coordinating Doctor must be satisfied that the person has understood the information discussed during the assessment. If the Coordinating Doctor is not satisfied that the person's decision is informed, the law will set out that they must assess the person as ineligible.

v. decision-making capacity

- 288. The law will state that a person can only be assessed as eligible for assisted dying if they have capacity to make an assisted dying decision. An assisted dying decision includes:
 - a. a decision to request an assisted death (at the point in time when decision to request an assisted death is made)
 - b. a decision to have an assisted death (at the point in time when a decision to have an assisted death is made).
- 289. The law will set out that a person has decision-making capacity in relation to assisted dying if they have the capacity to:

- a. understand any information or advice about an assisted dying decision that is required under the law to be provided to them
- b. understand the matters involved in an assisted dying decision
- c. understand the effect of an assisted dying decision
- d. weigh up the factors referred to above for the purposes of making an assisted dying decision
- e. communicate an assisted dying decision in some way (including verbally, using gestures or by other means).
- 290. In line with existing capacity legislation, the law will state that the person is assumed to have decision-making capacity in relation to assisted dying unless it is shown that they lack capacity.³⁶
- 291. Whilst the law sets out an assumption of decision-making capacity, the law also provides that the Coordinating Doctor must be satisfied that there is no evidence that the person lacks this capacity in relation to assisted dying. The Coordinating Doctor may have doubts about the person's capacity based on their interactions with the person, the person's medical history and / or information provided to them by third parties.
- 292. If the Coordinating Doctor is not satisfied (i.e., they think the person may lack capacity) or the Coordinating Doctor is unable to make a determination, the law will state that the Coordinating Doctor must seek supporting opinions or assessments from a relevant professional (i.e., a professional whom the Coordinating Doctor determines has the necessary expertise and training to make such a determination). Depending on the person's medical condition and any comorbid mental illness, suitable registered health practitioners may include a psychiatrist, geriatrician, psychologist or specialist social worker.
- 293. Supporting opinions or assessments may be required at any point during the process.
- 294. Having received and reviewed any additional professional opinions or assessments that may have been sought, the Coordinating Doctor must determine if they are satisfied that the person has decision-making capacity in relation to assisted dying. If they are not satisfied, the law will set out that they must assess the person as ineligible.
- 295. The Assessment Guidance will provide specific information to help support determination of decision-making capacity.
- 296. Capacity is time and decision-specific. This means the Coordinating Doctor should assess a person's ability to make a specific decision at the time the

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³⁶ Capacity and Self-Determination (Jersey) Law 2016 (jerseylaw.je)

decision needs to be made. Therefore, during the first assessment the person must demonstrate they want to make a request for assisted dying and participate in the assisted dying process. At the point of delivery, prior to the administration of the substance [step 7] the person must have decision-making capacity to make the decision to want to proceed with administration of the substance, with the capacity to understand it is going to result in their immediate death.

- 297. A person is considered to have decision-making capacity in relation to assisted dying if, in accordance with the assisted dying capacity test set out in paragraph 289 above, the person can understand the nature and effect of decisions and can demonstrate their understanding. They may require support to demonstrate this, and that support must be provided. Examples of appropriate support include (but are not limited to):
 - giving information to and receiving information from a person in a way that is tailored to their needs
 - communicating, or assisting a person to communicate, the person's decision, for example, with the assistance of an interpreter or communication support
 - giving a person additional time when discussing the matter with the person
 - using technology that alleviates the effects of a person's disability (for example, text-to-speech software could be used by a person who is unable to speak)
- 298. The law will set out that the assessing doctor and / or any other relevant professional who is assessing whether a person has decision-making capacity must take reasonable steps to conduct the assessment at a time and in an environment in which the person's decision-making capacity can be most accurately assessed, with support if required.
- 299. Some people may have fluctuating capacity, this means they may lack capacity to make a specific decision at one point in time but may be able to make the same decision at a later point in time. A person must be assessed as having capacity at each stage during the assisted dying process in order to progress past each step (i.e. at Step 1, Step 2 etc, all the way to their assisted death at Step 7). It is possible that in between these times, the person does not demonstrate decision-making capacity. This would not affect the determination of their eligibility.
- 300. All Assessment Forms will include the assessing doctors' / Administering Practitioner's confirmation of capacity at each stage.
- 301. A person with fluctuating capacity may be assessed for capacity on more than one occasion. If the person can demonstrate a voluntary, clear, settled and informed wish for assisted dying and that they have decision-making capacity to make the request for assisted dying one any one occasion, the assessing

doctor is able to determine that at the point of assessment they did have decision-making capacity.

Note: Ethical review – decision-making capacity

The Ethical Review noted that assisted dying "presents risks which indicate the need for stringent requirements regarding capacity and consent". It noted the proposals for an assisted dying capacity test in law and the presumption of capacity (in line with existing capacity legislation in Jersey).

The review authors recommended that "[consideration should be given to] removing the presumption in favour of capacity in the case of AD specifically, so that all applicants are routinely assessed."

Consideration has been given to removing the presumption of capacity, but it is proposed that it is retained, as presumed capacity is widely perceived as an important legal principle which ensures proper respect for personal autonomy by requiring any decision as to a lack of capacity to be based on evidence.

The review also noted that: "...we additionally suggest that (mandatory) training in assessing capacity and ensuring consent be provided, so as best to ensure compliance with the AD [assisted dying] law and guidance and consistency in practice." As detailed in Appendix 4: Outline of mandatory training, training in assessing capacity in relation to assisted dying will be developed as part of the assisted dying training for assisted dying practitioners.

Post first assessment determination

- 302. The Coordinating Doctor must inform the person of their decision and the reasons for that decision. There are two decisions that the Coordinating Doctor can make:
 - a. the person meets all the assisted dying eligibility criteria and can proceed to the next step in process; OR
 - b. the person does not meet one or more of the assisted dying eligibility criteria and cannot proceed to the next step in process
- 303. When informing the person of their determination, the Coordinating Doctor may decide others should be present to provide additional support. This could include the Care Navigator, another member of the MDT or a friend or family member who has been involved in the process.

Does not meet the criteria

304. If the person is assessed as not meeting the criteria by the Coordinating Doctor, the assisted dying process will stop unless the person requests a second opinion assessment. The Coordinating Doctor must confirm, in writing, to the person that their request for an assisted death has been declined and that the process has stopped. The Coordinating Doctor will note that the process has stopped on

the Assisted Dying Person Record. The person may choose to appeal the decision at this stage. [See section 8- Appeals]

Second opinion assessment

- 305. If the person requests a second opinion, this will be undertaken by an independent Second Opinion Doctor who is an assessing doctor who has not been involved in the person's request to date.
- 306. A second opinion may only be requested by the person. A third party, whether they are a family member or an attending practitioner or carer, cannot request a second opinion on the grounds that they are in disagreement with the determination that the person does or does not meet the criteria. Where a third party has a concern, they should raise that concern with the Coordinating Doctor who will be required, by law, to give due consideration to that concern. If the third party is not satisfied that their concern has been given due consideration, they may make a complaint (See Complaints/ safety concerns, after paragraph 351).
- 307. Further guidance on second opinions will be provided within the Assessment Guidance produced by the Committee.
- 308. The Second Opinion Doctor:
 - a. will be provided the Coordinating Doctor's completed first assessment report form and all copies of supporting assessments that may have been undertaken during the first assessment process
 - b. may make determination of eligibility based on a review of the first assessment report form and assessments alone (as, for example, there may be clear evidence that health criteria are not met and that a full assessment is not required) or the Second Opinion Doctor may deem it necessary to undertake a full first assessment.
- 309. It is for the Second Opinion Doctor to determine if a full first assessment is required or whether a review of the first assessment report form and assessments is sufficient. The person will not have a right in law to a full assessment if the Second Opinion Doctor determines that one is not required.
- 310. The Second Opinion Doctor will complete a Second Opinion Assessment Report form, the details of which will be prescribed by the Minister. This form will be part of the person's Assisted Dying Person Record. The Coordinating Doctor will inform the person of their determination of eligibility.
- 311. If the person is deemed at Step 2 as meeting the criteria by the Second Opinion Doctor:
 - a. The person may progress to the next step in the process which is assessment by the Independent Assessment Doctor (Step 3)

- b. the Coordinating Doctor will need to decide if they should continue to act in their role as Coordinating Doctor or whether another professional will need to take on this role, for example:
 - the Second Opinion Doctor
 - an entirely different assessing doctor.
- 312. This decision should be made in discussion with the person and the other professional who may take on the Coordinating Doctor role.
- 313. This decision will depend, in part, on whether the Coordinating Doctor agrees with the Second Opinion Doctor that the criteria are met, despite the Coordinating Doctor's assessment.
- 314. If it is decided that the role of Coordinating Doctor should transfer to another assessing doctor (whether this is to be the Second Opinion Doctor or another assessing doctor) an Assessing Doctor Transfer form must be completed (see below).
- 315. If the person is found by a Second Opinion Doctor not to meet the criteria at Step 2, the assisted dying process will stop. The person may choose to make an appeal to the Royal Court if the Second Opinion Doctor finds that they do not meet the criteria. [see section 8- Appeals]
- 316. The right to a second opinion will be a matter of practice and guidance, with the Assessment Guidance providing information as to the matters to be considered when determining the circumstances in which a request for a second opinion may be accepted or refused. A right to a second opinion will not be provided in law because of the potential that it could result in a vexatious use of resource, if a person who is clearly not eligible requests multiple second opinions.
- 317. A person may request a second opinion at both the first and second assessment, because there may be valid reasons for requesting a second opinion at each stage of the process. The Assessment Guidance will set out the circumstances under which it may be appropriate to request a second opinion at both stages of assessment.
- 318. If the person is found not to meet the criteria after a Second Opinion Doctor has made a determination of their eligibility, the Coordinating Doctor must communicate this decision to the person and confirm, in writing, to the person that their request for an assisted death has been declined and the process has stopped.
- 319. It may be difficult for a person seeking to access assisted dying to accept that they are not eligible. Following the decision, the person may continue to be supported by the Coordinating Doctor or the Assisted Dying Service MDT, particularly in relation to onward referrals for additional support. The

Coordinating Doctor should listen compassionately to the person and provide extra support where appropriate. This may include:

- acknowledging the person's disappointment or anger at the outcome of the assessment
- b. clearly explaining to the person why they are ineligible
- c. answering any questions the person or their support network may have
- d. providing details of the appeals process, where relevant
- e. discussing with the person how the healthcare team treating them may alleviate any physical symptoms, psychosocial and spiritual distress they may be experiencing
- f. providing referrals to relevant healthcare workers for psychosocial support (such as support from a social worker or psychologist)
- g. referring for additional support from a specialist palliative care team (if one is not already involved in the person's care)
- h. if relevant, explaining that the person's eligibility may change if their circumstances change, and the person may start the process again by making a new first request to the same medical practitioner or a different one, for example, if the person's prognosis changes, they may become eligible for assisted dying

Meets criteria

- 320. If the person is deemed to meet the criteria (whether by the first Coordinating Doctor or the Second Opinion Doctor) the Coordinating Doctor must ensure that it is established if the person wishes to proceed to a second, independent assessment by an Independent Assessment Doctor (Step 3) and the Step Transition form must be completed.
- 321. This task will generally be completed by the Care Navigator under the direction of the Coordinating Doctor.
- 322. The Coordinating Doctor (and / or the Second Opinion Doctor) may share supporting assessments and information with the Independent Assessment Doctor, but the Independent Assessment Doctor must make an independent assessment and must separately determine if the person is eligible for an assisted death before the person makes their second formal request (Step 4).

Assisted Dying Multidisciplinary Team

The Assessment Guidance will state that for each assisted dying request, a Multidisciplinary Team (MDT) will be formed to support the assessment process.

The requirement for an MDT, and the practice of the MDT will not be provided for in law.

The MDT will be chaired by the relevant assessing doctor and generally include a registered nurse, social worker and other relevant allied health professionals (e.g., speech & language therapist or dietician), depending on the needs of the person.

Each member of the MDT will have undergone the assisted dying training and will be registered with the Assisted Dying Service. If an MDT meeting is convened during the First Assessment stage it will chaired by the Coordinating Doctor (the Independent Assessment Doctor will not attend). If it is convened during the Independent Assessment stage it will chaired by the Independent Assessment Doctor (the Coordinating Doctor will not attend). Depending on the specifics of the person's request, the relevant assessing doctor who is chairing the meeting may also make a determination that other / different professionals needs to be included in the MDT.

The assessing doctor who is chairing the MDT will determine the frequency that the MDT meets during the assessment process, depending on the complexity of the case. The Assessment Guidance produced by the Committee will set out in detail how the MDT will operate.

All MDT meetings will be formally documented to provide a record of the discussions which will be included in the person's Assisted Dying Person Record (see paragraph 177).

The purpose of the MDT is to provide check and challenge for the assessing doctors and a multidisciplinary perspective to discussions of eligibility. The MDT meetings can be used to discuss if supporting or additional assessments may be required, and identify professionals who are best placed to provide this supporting opinion.

The MDT will also be a forum to discuss additional support that the person may require, this could be either:

- a. alongside the person's engagement in the assisted dying process for example, if the person would benefit from access to counselling services; or
- b. where the person is likely to be assessed as ineligible for assisted dying, the MDT may consider signposting to other services for example, if there are safeguarding concerns around financial abuse, a safeguarding referral should be instigated, and where there are ongoing social care needs, a referral for social care assessment should be instigated.

The assessing doctor may request that an MDT member provides a formal assessment or supporting opinion of the person. However, the determination of eligibility in the First and Independent Assessment will be made by the Coordinating Doctor and Independent Assessment Doctor respectively. (Conversely, the assessing doctor may also seek a formal assessment or supporting opinion from a professional who is not a member of the MDT. For example, an MDT social worker may input into MDT meetings, and support a person with onward referral if they are assessed as ineligible, but a non-MDT social worker may undertake an assessment of coercion / family dynamics.)

Supporting opinions / assessments from other professionals

The law will provide that an assessing doctor (including the Coordinating Doctor, any Second Opinion Assessment Doctors and the Independent Assessment Doctor) must seek a supporting opinion or assessment of specific matters related to a person's eligibility for assisted dying, if the assessing doctor is <u>unable to make a determination</u> on any of the criterion. They must have the person's prior consent to do so.

This must be a professional whose opinion the assessing doctor deems to be relevant to support them to make a determination – it may be a member of the assisted dying MDT or a professional outside of the Jersey Assisted Dying Service.

If the assessing doctor is able to make a determination, there will be no requirement in law to seek supporting opinions or assessments unless the person has been assessed as being on 'Route 2 - unbearable suffering' and the Coordinating Doctor is not an expert in the person's condition. In these circumstances, the law will set out that the Coordinating Doctor must seek opinion from a professional who does have expertise in the person's condition, unless the Coordinating Doctor is satisfied that the Independent Assessment Doctor has sufficient expertise.

This provision is made on the grounds that the law will not require assessing doctors to be experts in the person's condition (for example, if the person is dying of cancer, the assessing doctors do not need to be oncologists) as there may be no doctors with relevant expertise who have opted-in as assisted death practitioners. Whilst this is not seen as problematic where a person has a terminal illness with a short life expectancy (if the assessing doctors are confident they can make a determination of the person's eligibility), it is deemed essential to provide greater safeguards where a person is not expected to die in the shorter term.

The professional providing the professional opinion and carrying out supporting assessments will not be making an explicit determination of eligibility for assisted dying. They will instead be providing their opinion on matters which they are qualified to assess and determine in order for the assessing doctor to consider that opinion as part of the assessing doctor's determination of eligibility for an assisted death.

For this reason, professionals who are not physically present in Jersey may provide a professional opinion or supporting assessment on the matter they have been asked to provide detail on by the assessing doctor – for example a UK-based consultant may provide information about the person's prognosis / life expectancy because the consultant <u>is not</u> making any comment or determination of eligibility for assisted dying.

The opinion / assessment provided may relate to:

- a. the person's medical history, diagnosis, treatment options (for example, a respiratory consultant may provide opinion on treatment and care options), or
- b. their decision-making capacity to make the request for an assisted death, or

c. the voluntary, settled and informed nature of the person's wish (for example, a social worker providing an opinion on the context of family circumstances and the voluntariness of the person's request).

Those providing professional opinion and / or carrying out supporting assessments are not required to:

- a. have opted-in as assisted dying practitioner, or
- b. to undergo assisted dying training as they are not an assisted dying practitioner.

The professional providing the opinion and / or carrying out supporting assessments must be informed by the requesting assessing doctor that the opinion being sought relates to an assisted dying request. As set out in paragraph 94, the professional may then choose not to provide the opinion / assessment on conscious objection or other grounds.

Where the person chooses not to consent to the assessing doctor informing the relevant professional of their assisted dying request there can be no supporting opinions / assessment. The person must understand that this may mean the assessing doctor is unable to confirm eligibility.

Where the professional agrees to provide their opinion, they must complete a declaration of interest form stating:

- a. if they will be, or believe they may be a beneficiary under the will of the person, or if they may in any other way receive a financial or other material benefit resulting from that person's death; or
- b. if they know or believe that they are connected to the person in any other way that would affect their objectivity.

If any interests are declared, this will be risk assessed by the HCS Medical Director to determine if any interests declared potentially represent a conflict of interest. If it is determined there is a conflict of interest the Medical Director may direct the assessing doctor to seek the opinion of an alternative professional.

It is the assessing doctor who is responsible for the determination of eligibility. They may, therefore, adopt the opinion / determination provided to them, or they may choose to rely on their own determination. If they choose not to adopt the opinion / determination provided to them, they must have clear and robust reasons for doing so. Both the opinion / determination provided to them, and their subsequent decision-making, must be well documented on the Assessment Form.

It must be recognised that it is standard practice, for which doctors are trained to use their professional judgement, to make determinations that do not accord with the opinions or determinations of all other professionals.

Furthermore, it must be recognised that if the professionals seek advice, for example, regarding a different course of treatment for the person which may extend their life / alleviate their suffering:

- a. the person may choose to exercise right of refusal and not to accept the treatment, as no person should have to undergo treatment they do not want
- b. it may not impact on the person's eligibility, for example, the treatment could extend life by one month, but overall life expectancy may still be less than 6 months / 12 months.

Transferring the role of Coordinating Doctor (and other assessing doctor roles)

The law will set out that the role of Coordinating Doctor may be transferred to another eligible Coordinating Doctor from the Jersey Assisted Dying Service at any point in the request, assessment and approval process.

The person must be informed of this transfer by the Jersey Assisted Dying Service as soon as practicably possible.

Transfer of the Coordinating Doctor role may be required if, for example:

- a. the Coordinating Doctor makes a declaration or conflict of interest that the Medical Director determines, or the Doctor themselves determines, would impact on their ability to perform this role
- b. the Coordinating Doctor, following completion of the First Assessment, determines that the person is NOT eligible for an assisted death
- c. and; when a Second Opinion Assessment is requested and determines that the person has met the eligibility criteria. In this circumstance the Second Opinion Doctor may agree to assume the role of Coordinating Doctor.
- d. an unforeseen circumstance occurs (e.g., long term sickness, unplanned absence)
- e. the Coordinating Doctor wishes to recuse themselves for any other reason.

If the Coordinating Doctor role needs to be transferred, an Assessing Doctor Transfer form must be completed before the new Coordinating Doctor can take up the role, this must be signed by both doctors, where practicably possible. The form will be prescribed by Order by the Minister.

If the role of any other assessing doctor needs to be transferred—for example if the Independent Assessment Doctor had an unplanned absence part way through the Independent Assessment process—this will be carried out in the same way as a Coordinating Doctor transfer, as per the procedure outlined above.

Step 3: Independent assessment

323. The law will provide that before the Independent Assessment begins the person must confirm that they wish to proceed to the next step and for the assessment

- to be undertaken, which will be recorded on the Step Transition form by the Care Navigator or Coordinating Doctor. [see paragraph 161]
- 324. A second assessment will be undertaken by the Independent Assessment Doctor.
- 325. The Independent Assessment Doctor must, independently of the Coordinating Doctor, (and the Second Opinion Doctor, if relevant) form their own opinions on the matters to be determined, but in doing so, they:
 - a. may access any documentation arising from supporting opinions / assessment requests made by the Coordinating Doctor during the First Assessment
 - b. may consult with the Coordinating Doctor, members of the assisted dying MDT (or any other person engaged in the first assessment process) about matters relating to the person or the person's eligibility to meet the criteria.
 - c. However, they will <u>not</u> have access to the First Assessment Form completed by the Coordinating Doctor.
- 326. At any stage during this process the Independent Assessment Doctor may decide to convene an MDT meeting, but the Coordinating Doctor must not be in attendance. [See *Assisted Dying Multidisciplinary Team* after paragraph 322].
- 327. The purpose and format of the second assessment directly mirrors that of the first assessment (see from paragraph 232), i.e., it is for:
 - a. the Independent Assessment Doctor to determine if the person meets the eligibility criteria in law and, if so, confirm whether it is on the grounds of:
 - 'Route 1 terminal illness' [and if so, if the person's life expectancy is less than 14 days from the date of their First Formal Request]; or
 - 'Route 2 unbearable suffering'
 - b. for the person to fully explore, in dialogue with the doctor, their request for an assisted death and other care / treatment options.
- 328. The Independent Assessment will include exploration of the same matters relating to the nature of the person's request, treatment options, capacity etc.
- 329. The Independent Assessment Doctor will complete an Independent Assessment Report form which will form part of the person's assisted dying records. The details of the form will be prescribed by Order by the Minister.
- 330. If someone is providing communication, interpreting or advocacy support to the person at any point during the Independent Assessment, this must be recorded

- on the assessment form, and they must also sign the Independent Assessment Report Form.
- 331. The Independent Assessment Doctor (as per the Coordinating Doctor) must be satisfied that the person:
 - a. has understood the information discussed during the assessment
 - b. meets the all the eligibility criteria in law (excluding pre-assessed age and residency status)
- 332. As per the First Assessment, the Independent Assessment Doctor:
 - a. must seek further advice, professional opinion or additional assessment/s, as necessary, to support them in their determination.
 - this may include further opinion from professionals who have already been consulted during the first assessment and/or opinion and assessments from other professionals not previously consulted.
 - b. will continue discussions about the person's wishes and preferences for an assisted death, should they be found eligible, and the possible risks involved.

Post independent assessment

- 333. The Independent Assessment Doctor must inform the Coordinating Doctor and the Care Navigator of the outcome of the Independent Assessment.
- 334. The Independent Assessment Doctor must inform the person of their determination based on their assessment and the reasons for that determination. The outcome of the Independent Assessment Doctor's determination is that either:
 - a. the person meets all the assisted dying eligibility criteria and can proceed to the next step (Step 4) in the process; OR
 - b. the person does not meet the assisted dying eligibility criteria and cannot proceed to the next step in the process
- 335. The Independent Assessment Doctor may determine others should be present to provide additional support for the person when they tell them their determination. This could include the Care Navigator, another member of the MDT or a friend or family member who has been involved in the process.

Does not meet the criteria

336. If the person is assessed as not meeting the criteria the assisted dying process will stop unless the person requests a second opinion assessment. The

Independent Assessment Doctor must confirm, in writing, to the person that their request for an assisted death has been declined and that the process has stopped. The Independent Assessment Doctor will note that the process has stopped on the Assisted Dying Person Record. The person may choose to appeal the decision at this stage (see section 8 – Appeals).

- 337. If the person chooses to seek a Second Opinion Assessment, this will follow the process outlined in paragraphs 305 to 319.
- 338. It may be difficult for a person seeking to access assisted dying to accept that they are not eligible. Following the decision, the person may continue to be supported by the Coordinating Doctor or the Assisted Dying Service MDT, particularly in relation to onward referrals for additional support, see paragraph 319.

Meets criteria

If the person is deemed to meet the criteria (whether by the Independent Assessment Doctor or the Second Opinion Doctor), the Coordinating Doctor must ensure that it is established if the person wishes to proceed to making a Second Formal Request (Step 4). This task may be completed by the Care Navigator under the direction of the Coordinating Doctor and must be recorded in a Step Transition Form (see paragraph 161).

Step 4: Second formal request

- 339. The second formal request acts as confirmation of the person's enduring wish for an assisted death and will take the form of a written declaration.
- 340. The second request must be clear and unambiguous. It must be made in writing, using a Second Formal Request form as prescribed by Order of the Minister.
- 341. If the person making the request is physically unable to sign a written form, they may instruct someone to do so on their behalf. That may be any person aged 18 or over, who is not the Coordinating Doctor, the Care Navigator or any other involved professional, and must not be the person who is signing as a witness.
- 342. The request will take the form of a declaration, for example: I declare that I am making a second formal request for an assisted death. I make this request voluntarily and without coercion. My decision to have an assisted death is clear, settled and informed. My wish is a settled wish, made in full knowledge of alternative options for my ongoing care. I fully understand the nature and effect of this decision
- 343. If the person is eligible under 'Route 2 unbearable suffering', the person:
 - a. must consent to the relevant information [all assisted dying documentation held on their Assisted Dying Person Record] being shared with the Tribunal for the process to continue. If they do not provide this consent the assisted

- dying process will stop as the Tribunal cannot proceed to confirming the Coordinating Doctor's approval
- b. may consent to the Tribunal undertaking additional assessments (if they chose not to consent the Tribunal undertaking additional assessments the Tribunal may be unable to confirm the Coordinating Doctor's approval)
- c. may consent to the Tribunal calling on others who have not yet been involved in the assessment process (see paragraph 377).
- 344. If someone is providing communication, interpreting or advocacy support to the person, this must be documented, and they must also sign the Second Formal Request Form.
- 345. As with the first formal request, if the person making the request is physically unable to sign a written form, they may instruct someone sign on their behalf (see paragraph 220).
- 346. The person (and their signatory, if required), must make the second formal written request in the presence of a witness and an involved professional who must sign and date the request form attesting to:
 - a. the signing and dating of the request, in their presence;
 - b. that to the best of their knowledge, the person signing the declaration did so freely and voluntarily.
- 347. Or, if the declaration is completed by a signatory [where the person is physically unable to sign the written declaration], the witness must confirm that:
 - a. in the presence of the witness, the person appeared to freely and voluntarily direct the third person to sign the declaration; and
 - b. the third person signed the declaration in the presence of the person and in the presence of the witness.
- 348. The witness plays no role with respect to the assessment of eligibility or application of other safeguards.
- 349. The witness must be someone who knows the person sufficiently well, so that they feel able to attest to the fact the fact that the person is acting freely and voluntarily. This may be, for example:
 - an attending practitioner or carer who is providing care and treatment to the person, providing they have not been involved in the assisted dying application or assessment process
 - b. a friend, neighbour, someone who know the person in a personal or professional capacity.

- It cannot be a close family member, a beneficiary of the person's will or person who is likely to receive a financial benefit from the person's death.
- 350. The witness will be required to describe their relationship to the person on the Second Formal Request Form.
- 351. A witness is not required at the making of the first formal request as the primary purpose of the first formal request is to start the formal assessment process, whereas the second formal request has more significant implications as it is signifies continued intent to have an assisted death prior to approval.

Complaints / safety concerns

The Committee must bring forward an Assisted Dying Complaints and Concerns Policy to ensure there is a robust process in place to investigate and respond to:

- a. service standard complaints ("poor service complaint")
- b. safety concerns.

Poor service complaints

Given the nature of the assisted dying service, the complaints policy must ensure all complaints are investigated and responded to in the shortest possible timeframe.

A "poor service" complaint may be made, for example, by the person, their family or friends or any other attending practitioner and carer. Poor service complaints should, in the first instance, be considered and responded to by the Jersey Assisted Dying Service. Where the person who raised the poor service complaint is not satisfied with the response received, or the action taken, the complaint will be escalated in accordance with HCS complaints processes.

Even where the poor service complaint is resolved to the satisfaction of the complainant by the Jersey Assisted Dying Service, the Service will nevertheless provide a summary of all poor service complaints to the Committee.

Where the poor service complaint is made to someone other than the Assisted Dying Service, for example, to HCS's patient advisory services, it will be redirected to the Jersey Assisted Dying Service.

Safety concern / complaint

A safety concern may be raised by any person whether or not as part of a 'poor service' complaint. A safety concern may typically relate to concerns that one of the involved professionals or the Care Navigator is not acting in accordance with the law or is acting in such a way that their decision-making or actions may put a person at risk. This may include, for example, where a person has been assessed as eligible for an assisted death but a third party is concerned about the accuracy of this assessment.

Where a safety concern issue is raised this will initially be directed to the Assisted Dying Service who must immediately notify:

- a. the Committee
- b. the involved professionals
- c. HCS Quality and Safety group
- d. Jersey Care Commission
- e. the Tribunal, if relevant (see paragraph 368)
- f. the Court, if there is an appeal (see section 8 Appeals)

If the complaint relates to immediate patient safety concern, the assisted dying process for the person will be paused and a patient safety huddle will be convened to gather the facts. This should take place within 48 hours of the concern being reported and will generally include:

- a member of the HCS Quality and Safety Group, who will chair the meeting
- the Associate Medical Director of the HCS Quality and Safety Group
- the Involved Professionals for the assisted dying request(s) in question
- other relevant professionals who been involvement in the request in question, for example, a professional providing a supporting opinion or assessment.

Depending on the nature and severity of the incident, the HCS Quality and Safety Lead may extend the huddle to include the HCS Associate Managing Director and/or Associate Chief Nurse. Furthermore, the Group Medical Director or the executive on call will be briefed on the incident and they may attend the huddle.

If the safety complaint relates to individual member(s) of staff, they will not be involved in the huddle.

The Assisted Dying Complaints and Concerns Policy will set out that the Chair of the huddle must notify the HCS Serious Incident Panel within 72 hours. The HCS Serious Incident Panel must then review the notification and huddle information within 72 hours and make a decision as to whether a full investigation is required.

The Committee will be kept up to date with the progress of the investigation and ensure that any immediate concerns are escalated appropriately.

If the HCS Serious Incident Panel determine that a full investigation is required, the Panel may recommend to the Committee that assisted dying assessment process can continue but, if the person is approved for an assisted death, the assisted death may not go ahead until the safety concern is investigated by the appropriate agency and resolved (may be HCS as the employer of the assisted dying practitioner).

If the HCS Serious Incident Panel have no concerns having reviewed the complaint, and huddle outputs, they may advise the Committee that a full investigation is not required and recommend that the assisted death continues as planned.

At any point in the process, if it is deemed necessary, the matter may be escalation to any of the following: the JCC, HCS People Services team; the relevant UK professional regulatory body [GMC, NMC, HCPC, GPhC], the responsible officer who oversees the medical practitioner's GMC revalidation.

Escalation to the JCC will immediately take place where concerns relate to the Jersey Assisted Dying Service as a whole, rather than an individual professional.

The Committees' Complaints and Concerns Policy will also outline circumstances under which the assisted dying process for a person should be immediately suspended pending investigation.

Step 5: Approval process

Administrative Review by Coordinating Doctor (approve or decline) and Tribunal confirmation of approved requests [Route 2 only]

Administrative Review by Coordinating Doctor

- 352. If the person has made a first and second formal request and has been determined as eligible for assisted dying at both a first and second independent assessment (whether by a Coordinating Doctor / Independent Assessment Doctor or a Second Opinion Doctor), the person may decide to proceed to the next stage (Step 5) the administrative review to approve or decline the assisted dying request.
- 353. Before the Coordinating Doctor undertakes the review, the person must confirm that they wish for review to be undertaken (including consent to review by Tribunal for those eligible under Route 2 unbearable suffering), which will be recorded on the Step Transition form (see paragraph 161).
- 354. The Step Transition form will be completed by the Coordinating Doctor, in discussion with the person, as part of Step 4 second formal request.
- 355. During Step 5 the Coordinating Doctor will undertake a full and final review to check all the documentation for assessing eligibility for assisted dying has been properly completed and to ensure that all the appropriate formal requests are in place. This will include review of:
 - a. referral documentation

- b. First Formal Request
- c. First Assessment Report form (and any additional documentation related to supporting opinions/assessments)
- d. documentation from the Assisted Dying Multidisciplinary Team meetings
- e. Independent Assessment Report Form (and any additional documentation related to supporting opinions/assessments)
- f. Second Opinion Assessment Report form(s), if relevant
- g. Second Formal Request form
- 356. The Coordinating Doctor will complete an Administrative Review (approve or decline) form, the details of which will be prescribed by Order of the Minister.
- 357. If any documentation is not in place or is incorrect, OR the Coordinating Doctor identifies any errors of process OR identifies that the person is not eligible (for example, if some critical information has been overlooked) the Coordinating must take action to resolve. This may include:
 - a. ensuring that the documentation is completed correctly, and that any changes at this stage are recorded on the Administrative Review Form
 - b. potentially repeating a Step in the process.
- 358. The Coordinating Doctor cannot sign the 'approval' section of the Administrative Review Form unless the Coordinating Doctor is satisfied that the following conditions have been met;
 - a. the process has been followed in full;
 - b. all the necessary documentation is in place; and
 - c. the person meets all the eligibility criteria.
- 359. In the event of any delays completing the Administrative Review the Coordinating Doctor must ensure the person is kept fully informed.
- 360. In the event that Coordinating Doctor determines they cannot approve the request, the person must be informed that their request has been declined, explaining the reasons for this and supporting them in the same way as indicated for those who are determined as ineligible after either the first or second assessment (see paragraph 319).
- 361. The Coordinating Doctor must also confirm, in writing, to the person that their request for an assisted death has been declined and that the process has stopped. The Coordinating Doctor will note that the process has stopped on the Assisted

Dying Person Record. The person may choose to appeal the decision at this stage (see section 8 – Appeals).

Route 1 (terminal illness) approval

- 362. If the Coordinating Doctor is satisfied that the conditions above have been met, they will sign the Route 1 approval section on the Administrative Review Form which confirm the person's request for an assisted dying has been approved.
- 363. The person will be informed in writing, and the Coordinating Doctor will establish if the person wishes to proceed to the care planning stage for their assisted death (Step 6). Informing the person and establishing the wish to proceed to Step 6 may be completed by the Care Navigator under the direction of the Coordinating Doctor and will be recorded on the Step Transition Form (see paragraph 161).
- 364. For 'Route 1 terminal illness' approvals, there must be at least two working days between the Administrative Review (approve or decline) form being approved and signed (Step 5) and the final review before the assisted death (Step 7) to allow for appeals. [Unless the person has a life expectancy of less than 14 days from the date of their first formal request, in such cases the 2 working days minimum timeframe would be waived (see paragraph 174).]
- 365. The Care Navigator, having confirmed that the person has signed the Step Transition form will then provide a copy of the Route 1 approval section of the Administrative Review form to the Administering Practitioner (where this is a person other than the Coordinating Doctor). This will allow the process to move to Step 6 Assisted death care planning (see paragraph 418).

Life expectancy of less than 14 days

- 366. In the event that the person has a life expectancy of less than 14 days (since the date of their first Formal Request) both the Coordinating Doctor and Independent Assessment Doctor must be of the opinion that the person has a life expectancy of less than 14 days, and have recorded this on the First Assessment form and Independent Assessment form.
- 367. At the point of First Assessment and / or Independent Assessment, the person's life expectancy may be determined to be more than 14 days, but this may decrease due to a rapid or unexpected decline in their condition. If this is the case, and both the Coordinating Doctor and the Independent Assessment Doctor are of the opinion that the person's life expectancy is now less than 14 days, the 14-day minimum timeframe may be disapplied but both the Coordinating Doctor and the Independent Assessment Doctor must sign the Administrative Review (approve or decline) form to confirm this.

Route 2 (unbearable suffering) approval – Tribunal

- 368. If the Coordinating Doctor has determined that the conditions above have been met (see paragraphs 352-358), they will sign the Route 2 approval section on the Administrative Review form to confirm to the person in writing that the person's request for an assisted dying has been provisionally approved. The law will provide that a special Tribunal must review the Route 2 approval decision made by the Coordinating Doctor and must either confirm or decline that approval.
- 369. The Jersey Assisted Dying Service must ensure that the Administrative Review (approve or decline) form and all documents from the person's assisted dying record is provided to the Tribunal within two working days of the Coordinating Doctor signing the approval section.
- 370. The Tribunal will not review a Coordinating Doctor's decision to refuse an assisted dying request. They will only review a Coordinating Doctor's decision to approve an assisted dying request. Any review of a refusal decision will be via appeal to the Royal Court (see appeals section below).
- 371. The rationale for the Tribunal <u>not reviewing</u> a decision <u>not to approve</u> an assisted dying request is:
 - a. it avoids a multi-stage process which could involve review by the Tribunal, followed by appeal to the Court, which would simply serve to create increased uncertainty, stress and delays for the person; and
 - b. if the Court finds, on appeal, that the assessing doctors' opinion was wrong, and the person meets the eligibility criteria, there is a remedy (i.e., the Court can approve the request).
- 372. The rationale for the Tribunal always reviewing a decision to approve an assisted dying request is that it provides an extra safeguard. If the Coordinating Doctor's decision to approve an assisted dying request is wrong, there is no remedy as the person will be dead (unless there is a successful Royal Court Appeal) and the consequences of this are more significant where the person is experiencing unbearable suffering but does not have a terminal illness with the associated limited life expectancy.
- 373. The Tribunal will form part of the Tribunal Service (a department of the Court Services of the Judicial Greffe established to hear certain types of claims and appeals under various laws).
- 374. The function of the Tribunal is to review the approval decision made by the Coordinating Doctor. The Tribunal, having undertaken that review may determine to:
 - a. confirm the Coordinating Doctor's approval of the request
 - b. reject the Coordinating Doctor's approval of the request.

- 375. A determination by the Tribunal to confirm or reject the Coordinating Doctor's approval may be made on the basis of the information provided by the Jersey Assisted Dying Service if the Tribunal is satisfied by the relevant information.
- 376. Relevant information refers to all data held on the person's Assisted Dying Person Record which includes:
 - a. Referral documentation
 - b. First Formal Request form
 - c. all Declaration of Interest forms signed by the involved professionals and Care Navigator
 - d. all Step Transition forms and Assessing Doctor Transfer forms
 - e. First Assessment Report form
 - f. Independent Assessment Report form
 - g. any Second Opinion Assessment Report forms
 - h. Second Formal Request form
 - i. Administrative Review (approve or decline) form
 - j. any other supporting documentation or relevant documentation, including additional assessments or advice and opinions that formed part of either the first or independent or second opinion assessment.
 - k. records of any appeals
- 377. If the Tribunal is not satisfied with the relevant information provided, they may:
 - a. request further assessments of the person
 - b. compel any person who has already been involved in the assessment process to provide additional information, evidence or testimony (in writing, in person, via video-link) which will support the Tribunal to reexamine the information they have been provided. These persons may include:
 - i. the person
 - ii. the Coordinating Doctor or the Independent Assessment Doctor (plus any Second Opinion Doctors)
 - iii. Care Navigator or other staff from the Jersey Assisted Dying Service

- iv. other professionals who provided supporting assessments
- v. other attending practitioners and carers
- vi. friends or family
- vii. any other person that the Tribunal deems relevant
- c. compel people who have not, to date, been involved in the assessment process to provide additional information, evidence or testimony but only where the person has given their consent for them to be involved in the process (for example, family and friends).
- 378. The law will provide that, as part of the second formal request that relates to 'Route 2 unbearable suffering', the person:
 - a. must consent to the relevant information being shared with the Tribunal
 - b. may consent to the Tribunal undertaking additional assessments
 - c. may consent to the Tribunal calling on others who have not yet been involved in the assessment process.
- 379. If the person declines to give their consent to the Tribunal undertaking additional assessments or calling on others, they must be advised that this may impact the Tribunal's ability to make a determination.
- 380. It will be for the Tribunal to determine who it hears from, except that the Tribunal must hear from the person, if the person determines they wish to be heard. The law will provide that the Tribunal must ensure the person is provided an opportunity to state whether they wish to be heard.
- 381. In hearing from the person, the Tribunal will need to give due consideration to the burden placed on the person. Testimony may be heard, for example, via an in-person visit by all / some members of the Tribunal to the person in their place of care or a video-link.

Establishing the Tribunal

- 382. The Bailiff will appoint and maintain an assisted dying Tribunal panel from which the members of an assisted dying Tribunal will be convened.
- 383. Each Tribunal convened will consist of:
 - a. 1 x legal member (the Chair) advocate or solicitor of Royal Court for 5-years minimum
 - b. 1 x medical member medical practitioner with relevant experience

- c. 1 x lay member.
- 384. Tribunal members must not be:
 - a. a States member, Bailiff or Jurat
 - b. any attending practitioners or carer involved in the care and treatment of the person
 - c. anyone who is a beneficiary under the will of the person or may in any other way receive a financial or other material benefit resulting from that person's death.
- 385. The Minister will establish remuneration for panel members by Ministerial Decision.
- 386. The law will provide that the Tribunal must review the decision made by the Coordinating Doctor to approve the assisted dying request within a maximum of 30 days. 'Day 30' being the last day the Tribunal can issue their determination and 'Day 1' being the day the Tribunal receive the relevant information from the Jersey Assisted Dying service.
- 387. There will be an advanced notice process to support Tribunal planning. The law will set out that the Jersey Assisted Dying Service must ensure that:
 - a. the Tribunal service is alerted to the possible need for Tribunal determination as soon a practicably possible after a person is assessed at Step 2 by the Coordinating Doctor as meeting the 'Route 2 unbearable suffering' eligibility criteria
 - b. a follow up alert is issued immediately after the Independent Assessment Doctor confirms eligibility under 'Route 2 unbearable suffering' at Step 3 in the process
 - c. the Jersey Assisted Dying Service will formally notify the Tribunal service of the need to set up a Tribunal hearing within 2 workings days of the Coordinating Doctor signing the Route 2 approval section on the Administrative Review, at which point the Jersey Assisted Dying Service must also provide the Tribunal service with all relevant information.
- 388. Following a decision on eligibility by the Tribunal to confirm or reject the Coordinating Doctor's approval of the request, an application may be made to the Royal Court for appeal. [see Appeals section]. An appeal of the Tribunal's decision may be made on a point of law only.

- 389. There must be at least two working days between the determination of the Tribunal (Step 5) and the final review before the assisted death (Step 7) to allow for appeals (see appeals).
- 390. For all approved Route 2 assisted deaths, the Tribunal Chair will be required to ensure that any formal documentation produced by the Tribunal is provided to the Assisted Dying Review Panel within 2 working days of being notified of the death of the person by the Administering Practitioner.

Note: Establishing a specialist Tribunal

The resource implications will include:

- set-up and recruitment costs
- accommodation and other fixed costs, including administrative support
- remuneration of Tribunal members (whilst the Tribunal is sitting and in the preparation stage)
- ongoing training requirements
- costs involved in making a determination (including additional medical assessments).

There may be inherent difficulties in ensuring the Tribunal has the skills and knowledge necessary to make assisted dying determinations. This is partly because:

- the Tribunal would sit on relatively irregular basis as the number of assisted deaths eligible under 'Route 2' in Jersey is expected to be between 0 and 2 deaths per year (based on the number of assisted deaths under 'Route 2' in Canada, which accounted for 3.5% of all assisted deaths and 0.15% of all deaths in Canada in 2022.³⁷ It is estimated that there would be between 2 to 38 assisted deaths per year in Jersey) and only those following 'Route 2 approval' would go to Tribunal
- individuals with the prerequisite skills may decline to participate in an assisted dying Tribunal.

Expiry of approval

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- 391. Once a person has had an approval for assisted dying (or their approval confirmed in the case of Route 2) the law will set out that there will be no expiry date for this approval.
- 392. Approaches to expiry of approval varies by jurisdiction, but there is no expiry date associated with approvals in most other jurisdictions; New Zealand being

³⁷ Fourth annual report on Medical Assistance in Dying in Canada 2022 - Canada.ca

- an exception where approval expires six months after the date initially chosen for the administration of the substance.³⁸
- 393. The decision to not include an expiry date is a safeguard, so that pressure is not placed on the person to end their life through an assisted death when they are not yet ready to do so, purely because their approval is close to expiry.
- 394. An approval for an assisted death can have a palliative effect, providing the person with a sense of control over the end of their life. Evidence from other jurisdictions suggests that, in some cases, the knowledge that a person has the option to end their suffering brings such comfort that they choose not to proceed to an assisted death. For example, in Western Australia in 2022 around 28% of people who were approved for an assisted death, did not go on to have an assisted death.³⁹

Section 8: Appeals

This section outlines the proposed appeals process.

Page - 114

³⁸ End of Life Choice Act 2019 No 67 (as at 28 October 2021), Public Act 20 Administration of medication – New Zealand Legislation

³⁹ Voluntary Assisted Dying Board Western Australia Annual Report 2022-23 (health.wa.gov.au)

- 395. The law will set out an appeals process. Clear information about the appeals process will be given to all persons who request an assisted death. The information will also be available online.
- 396. Appeals will be made to the Royal Court, which will sit as the Inferior Number to make a determination this will consist of the Bailiff, Deputy Bailiff or a Royal Court Commissioner sitting with two Jurats. [As opposed to the Superior Number which consists of the Bailiff, the Deputy Bailiff or a Royal Court Commissioner and a minimum of five Jurats]
- 397. Whilst most jurisdictions do not provide for an appeal process within their assisted dying legislation (an exception being some Australian states), it is proposed that provision is made in Jersey law to provide for a right of appeal to the Court, which in turn will help support public confidence in the assisted dying process.
- 398. The law will provide that there must be a minimum of 2 working days between an approval being made by the Coordinating Doctor under 'Route 1 terminal illness', or the Tribunal confirming a Coordinating Doctor's approval under 'Route 2 unbearable suffering' and the administration of the substance at Step 7 the assisted death, unless:
 - a. the person, eligible under 'Route 1', has a life expectancy of less than 14 days from the date of their first formal request, and in such cases the minimum timeframe would be waived and there would be no right to appeal.
- 399. The 2 working days' time period will provide an opportunity for a person (for example, a family member) to make an application to appeal, but only where that person is aware of the assisted dying application in the first instance (whilst the assessing doctors will encourage persons to involve their family and friends they may have chosen not to do so, hence there is a possibility in a small number of cases where family and friends may not be aware of the request at any point in the process).
- 400. 2 working days is a limited period of time, but it aims to strike a balance between giving time for third parties to appeal, whilst not significantly impeding the assisted dying process where the person wishes to proceed.
- 401. In addition, an application to appeal must be made within a maximum of 28 days following the approval decision by Coordinating Doctor under Route 1 or confirmation of approval, under Route 2 (if the person has not already proceeded to Step 7 (assisted death) following the minimum time period). This time period is in line with other tribunal processes within Jersey, and with other assisted dying appeals processes, such as Western Australia.
- 402. The appeals process is in addition to the ability of a person to request a second opinion from a doctor as part of the first assessment process (Step 2) and the

independent assessment process (Step 3) and the complaints process set out by the Committee.

- 403. An appeal can be made in relation to:
 - a. a Route 1 (terminal illness) request that was approved
 - b. a Route 1 (terminal illness) request that was not approved
 - c. a Route 2 (unbearable suffering) request that was not approved by the Coordinating Doctor
 - d. a Route 2 (unbearable suffering) request that the Coordinating Doctor approved, and the Tribunal confirmed, but only on a point of law
 - e. a Route 2 (unbearable suffering) request that the Coordinating Doctor approved, and the Tribunal rejected, but only on a point of law.
- 404. Route 2 (unbearable suffering) appeals that have been to Tribunal can only be reviewed on a point of law as the Tribunal will already have covered all other matters in their examination of the approval.
- 405. The grounds for appeal will not include matters relating to the determination of the person's diagnosis and prognosis as detailed consideration of the diagnosis and prognosis is already provided for in the assessment process.
- 406. The grounds of appeal will only relate to:
 - a. a decision of the Coordinating Doctor to accept a determination that the person has been, or has not been, ordinarily resident in Jersey for at least 12 months. For clarity, the person who has not been resident for at least 12 months cannot appeal to the Court to allow them an assisted death. The appeal to the Court will only relate to whether the period of residency has been correctly determined (i.e., "they say I haven't been resident for 12 months, but I have")
 - b. a determination taken by any of the assessing doctors that:
 - the person has the decision-making capacity to request an assisted death
 - the person does not have the decision-making capacity to request an assisted death
 - the person's wish is voluntary, clear, settled and informed
 - the person's wish is not voluntary, clear, settled and informed
 - c. a failure, or perceived failure, to make determinations or act in accordance with the process set out in law (i.e., service failing or maladministration).

- 407. The following people may appeal to the Royal Court:
 - a. the person who has requested the assisted death
 - b. an agent of the person who has requested the assisted death (i.e., someone who the person has asked to act on their behalf); or
 - c. any other person who the Court is satisfied has a special interest in the care and treatment of the person
- 408. A person with special interest in the care and treatment of the person may be a family member or close personal friend. This will not include an unconnected third party (such as a representative of a lobby group) who is appealing on the basis that they do not support assisted dying. It is up to Court to determine if the person making the application for review is eligible to do so. Being a relative of the person accessing assisted dying does not mean the applicant is automatically considered to have a sufficient and genuine interest.
- 409. A person with a special interest in the care and treatment of the person may only appeal a decision to approve a 'Route 1 terminal illness' or 'Route 2 unbearable suffering' request. They cannot appeal a decision not to approve an assisted dying request.
- 410. Following an appeal that relates to 'Route 1 terminal illness' approval / non-approval or to 'Route 2 unbearable suffering' non-approval the Court may either uphold or overturn the Coordinating Doctor's decision by determining that:
 - a. the person is eligible for an assisted death
 - b. the person is not eligible for an assisted death.
- 411. Following an appeal that relates to a decision made by the Tribunal, the Court may decide that:
 - a. the Tribunal's determination should stand (and approval for an assisted death is or is not given)
 - b. the Tribunal's determination should not stand (and approval for an assisted death is or is not given).
- 412. A determination must be made within 7 working days of the application being made.
- 413. The decision of the Royal Court will be final. There will be no further right of appeal.
- 414. The law will provide for the making of Court Rules related to assisted dying appeals. This may include matters relating to:

- a. provision of further evidence, information or testimony and associated timeframes
- b. notification procedures at the point at which an appeal application is submitted, as it is imperative that the assisted dying process is immediately suspended until the Court has ruled.
- 415. If the Court determines that the person is eligible for assisted dying the assessment and delivery process may continue.
- 416. If the Court determines that the person is ineligible for assisted dying the assessment and delivery process ends. This does not preclude the person from making another First Request if the situation giving rise to the Court decision changes.
- 417. The determination of the Royal Court is final, with no right to onward appeal.

Section 9: Assisted dying process – planning and delivery of an assisted death

This section details Steps 6 to 8, how a person who has been approved for assisted dying will be supported to plan for their assisted death, the process for prescribing and

dispensing the assisted dying substance and the provision of the assisted death. This section also sets out the process for what happens after the assisted death. These are the steps to ensure that an assisted death is carried out safely and in accordance with the law.

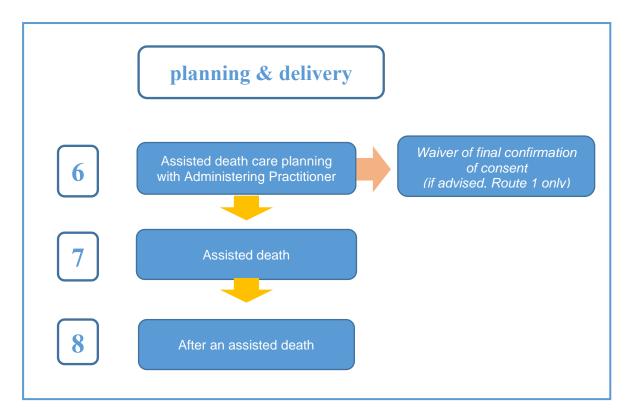


Figure 3 – process steps for planning and delivery of an assisted death

Step 6: Assisted Death Care Planning

Assisted Death Care Planning

- 418. During the planning and delivery phase the Administering Practitioner (as distinct from the Coordinating Doctor) becomes the principal clinician responsible for the care and support of the person. The Administering Practitioner may be a doctor or a registered nurse.
- 419. The Administering Practitioner may be the Coordinating Doctor or a registered nurse who supported the assessment process as a member of the assisted dying MDT, but it may not be the Independent Assessment Doctor as, by definition, they are independent.
- 420. The Care Navigator will liaise with the person and the Coordinating Doctor to agree assignment of an Administering Practitioner (if the Administering Practitioner is a different person from the Coordinating Doctor).

- 421. The person will only move to the Step 6 assisted death care planning once they have an approval for an assisted death, either from the Coordinating Doctor (Route 1) or confirmation of the Coordinating Doctor's approval from the Tribunal (Route 2). As with all other steps in the process, the person will determine the pace and their decision to proceed to Step 6, and this decision must be recorded in a Step Transition form before Step 6 may proceed (see paragraph 161).
- 422. The person will be supported by Jersey Assisted Dying Service with the care planning for their assisted death, with involvement from the:
 - a. Care Navigator
 - b. Administering Practitioner
 - c. Assisted Dying MDT members, where required
 - d. Pharmacy Professionals.
- 423. The planning and preparation phase allows for the person and the Administering Practitioner to prepare an assisted death plan which accords with the person's wishes and preferences, as far as possible, for an assisted death. The Assisted Death Care Plan form will be prescribed by Order of the Minister. Assisted Death Care Planning Guidance will be developed by the Committee.
- 424. Discussions with the person about their wishes that began during the First Assessment (Step 2) will continue throughout the process and will have been recorded on the assessment forms. The Administering Practitioner will review this information prior to meeting with the person to develop their Assisted Death Care Plan as, in many cases, the process will consist of confirming previously stated wishes.
- 425. The Assisted Death Care Plan will set out:
 - a. the preferred method for an assisted death (self-administered or practitioner administered) including discussion of the assisted dying substance that will be used, so that the person can give informed consent.
 - b. the assisted dying practitioners who will be present at the assisted death this must include the Administering Practitioner. And if the death is to take place in a private residence. [The Assisted Death Care Planning Guidance will state that one other member of the Assisted Dying Service must also be in attendance, for example a registered nurse from the MDT or the Care Navigator.]
 - c. if any of the following consents or waivers are in place:
 - Confirmation of Consent to Proceed

- Waiver of Final Confirmation of Consent ('Route 1 terminal illness' only)
- Any Advance Decision to Refuse Treatment (ADRT), including a DNACPR (Do Not Attempt Cardiopulmonary Resuscitation)
- d. the names of any family members or friends who will be present at the death, including how they will be supported to understand what happens during the dying process and what, if anything, they need to do at that time (for example, supporting the person to self-administer the substance)
- e. any cultural considerations and rituals that are important to the person and their family and that they wish to observe at the bedside
- f. the location where the person wants to be at the end of their life.
- 426. The Assisted Death Plan must be signed by the person and the Administering Practitioner, if the person making the request is physically unable to sign a written form, they may instruct someone to sign on their behalf.

Approval of location

The law will provide that possible locations for an assisted death include:

- a. private homes
- b. care and nursing facilities owned by GoJ or managed by GoJ
- c. care and nursing facilities not owned by GoJ (these may be privately owned, parish-owned or owned by a charity or community organisation)
- d. hospital facilities.

The law will state that in each case the location must be approved by the Administering Practitioner. A location cannot be approved by the Administering Practitioner unless:

- a. permission has been given for an assisted death to take place at that location, for example, if the person wishes to die in their residential care home (or similar) the consent of the care home manager or provider will be required. The care home provider may choose to conscientiously object or not provide consent on other grounds (for example practicalities or the potential impact on other residents)
- b. the Administering Practitioner is satisfied that an assisted death can be safely supported in that location, for example, if the person wishes to die at home but lives in shared accommodation with people who are opposed, the Administering Practitioner will need to consider whether that may result in disruption and / or distress and / or potential harm.

The Minister will publish Location Guidance which will set out that appropriate plans must be made. For example, if the assisted death is to take place in a care facility, there will need to be consideration of other individuals that may be present or close by during the assisted death (for example, persons and staff in the same hospital ward, even if the assisted death takes place in a private room).

Whilst the Administering Practitioner must approve the location, discussions will have taken place throughout the assessment process and the Care Navigator will, in most cases, have undertaken the checks necessary for the Administering Practitioner to give location approval.

If the person's preferred location cannot be approved or is unlikely to be approved by the Administering Practitioner, the Care Navigator will work to identify an alternative location for the person to consider.

To ensure consistency, the law will provide that the Administering Practitioner will be responsible for final approval of the location. This may, however, create practical problems if it only becomes apparent at a late stage that a location is not appropriate. To mitigate against this potential, albeit unlikely event, the person will be asked to state both their preferred place of death and an alternative place. The alternative place must be a place where it is known that approval will be given (for example, an appropriate hospital facility).

Assisted deaths will be permitted in GoJ care facilities but, as above, appropriate plans must be put in place to provide for others being cared for, or working in, that facility.

Confirmation of consent to proceed

The assessing doctors will talk with the person about whether they wish to provide confirmation of consent to proceed. Any consent given will be recorded on the Assisted Death Care Plan (and the Assisted Dying Patient Record).

Confirmation of consent to proceed allows the Administering Practitioner who will be present at the assisted death, to take an appropriate intervention, such as administering the substance intravenously, in the event the person loses decision-making capacity but does not die during the process of administering the substance (for example, if they have opted to self-administer the substance and have digested some but not all of it).

Specific consent will be requested for the advance placement of an IV line (if taking the assisted dying substance orally) in order to administer additional assisted dying substance intravenously, in the event of either:

- a. medical complications that prevent the completion of the assisted death, including regurgitation and vomiting, or seizure
- b. delayed effectiveness of oral medication, where the person has not died within 60 minutes of taking the substance orally.

A person is advised, but not required to provide confirmation of consent to proceed.

Waiver of Final Confirmation of Consent

The law will provide that a person who is eligible under 'Route 1 – terminal illness' may make a 'Waiver of Final Confirmation of Consent'. This allows a person to decide in advance that, if they lose decision-making capacity AFTER their request for an assisted death has been approved (Step 5) but BEFORE they are due to confirm their consent for a final time during the 'final review' (at Step 7), the assisted death can still take place.

The rationale for 'Waiver of Final Confirmation of Consent' is that it ensures a person, who has been approved as eligible and has consented to have an assisted death, will not be prevented from having their request fulfilled (in accordance with previously agreed arrangements) if their health condition deteriorates rapidly to the point at which they lose their decision-making capacity to provide final confirmation of their consent, before the assisted death takes place.

The Waiver of Final Confirmation of Consent is a written declaration which the person may choose to make as part of their care planning, but which does not become valid until their Assisted Death Care Plan – which must set out the preferred date, location and mode for their assisted death - has been agreed and signed by both the person and the Administering Practitioner.

The law will provide that a Waiver of Final Confirmation of Consent can only be made:

- a. if the person's request for an assisted death has been approved under 'Route 1 terminal illness'; and
- b. the person has decision-making capacity at the time they sign the Waiver

Assisted Care Planning Guidance will state that the Administering Practitioner should inform the person about the option to sign a Waiver of Final Confirmation of Consent, and if the person is at risk of losing their ability to give consent to assisted dying the Administering Practitioner must inform them of this.

In the event the waiver needs to be relied on - because the person has subsequently lost decision-making capacity - the Administering Practitioner can proceed to administer the substance that will cause their death. The Administering Practitioner will seek to do so in accordance with the Assisted Death Care Plan (although the Administering Practitioner may be required to make some adjustments, for example, to the way in which the substance is administered in recognition of the deterioration in the person's health).

For the purpose of clarity:

a. The person is not required to provide a Waiver of Final Confirmation of Consent. If they do not, and they lose capacity between after their request has been approved (Step 5) and before they are due to give their final consent (Step 7), the assisted death cannot take place.

b. Even if the person has in place a Waiver of Final Confirmation of Consent in place the process will not proceed if, during the final review or in the lead up to the assisted dying substance being administered, the person demonstrates a refusal or resistance to the administration of the substance by words, sounds or gestures (for clarity, reflexes and other types of involuntary movements, such as response to touch or the insertion of a needle, would not constitute refusal).

Advance Decision to Refuse Treatment

The 2021 Citizens' Jury recommended that people were provided an opportunity to make an advanced decision to have an assisted death. Advance decisions are a mechanism via which people, with decision-making capacity, set out the types of care and treatment they do, or do not want, in the event they lack decision-making capacity at some point in the future. For example, if they are in a coma or lose capacity due to dementia.

If advanced decisions were permitted for assisted dying this would allow a person to say, for example: "I want an assisted death if, at some point in the future, I have advanced dementia and I can no longer move, eat or speak".

Most jurisdictions do not permit advance decisions, the exceptions being the Netherlands, Spain and Belgium (in limited circumstances, for example if the person is in a coma but not if they have been diagnosed with dementia)

Whilst advanced decisions, under limited circumstances were supported by a small majority of the Jury [the report did not state under which circumstances they were in favour of], they were not brought forward in P95/2021 proposals on the basis that sufficient safeguards could not be guaranteed. The assisted dying assessment process has been developed to ensure that the person requesting assisted dying must have decision making capacity and can consent to requesting assisted dying throughout the assessment and approval process – which could not happen if a person made an advance decision months or years in advance of their assisted death taking place. [This is in contrast to the Waiver of Final Confirmation of Consent above- where the person must have capacity up to the point of approval]

Whilst advanced decisions for an assisted death will not be permitted in law (i.e., a person will not be able to specify the circumstances in which they want an assisted death) Advance Decisions to Refuse Treatment (ADRT) will be permitted, as in any other end of life circumstances in Jersey.⁴⁰

As part of the care planning process, the Guidance will state that the Administering Practitioner must discuss with the person whether the person wishes to have in place an Advance Decision to Refuse Treatment (ADRT). An ADRT could include a DNACPR - do not attempt cardiopulmonary resuscitation – providing clear instruction to health care providers that the person does want to be resuscitated if the person requires emergency medical treatment during any step of the assisted dying process.

⁴⁰ Advanced decision to refuse treatment (ADRT) (gov.je)

- 427. The Administering Practitioner must arrange for a dedicated assisted dying registered medical practitioner (ADRMP) to attend to the person at this stage if this has not already taken place. The ADRMP, who will be responsible for certifying the death of the person, must by law have attended the person within the 14 days prior to their death (See paragraph 483).
- 428. The Administering Practitioner must also inform the Jersey General Hospital Pharmacy once the Assisted Death Care Plan has been agreed and signed by the person, informing them of the intended date of the assisted death.
- 429. The Care Navigator will support the person to involve their family and friends in the planning or in communicating the plan to family and friends, if the person so wishes, as those who will be present at the death should be aware of these details in advance. The final decisions, however, rest with the person.
- 430. There will be further discussion of potential medical complications and what may happen in those circumstances, particularly if there is no consent to proceed or Advance Decision to Refuse Treatment in place.

Prescribing, preparing and dispensing the assisted dying substance

- 431. 'Assisted dying substance' refers to the combination of drugs/medications, used for the purpose of causing the person's assisted death. The Committee will approve the authorised drug regimen i.e., the combination of drugs which may be prescribed as the assisted dying substance, see paragraph 445 below.
- 432. Prescribing and Dispensing Guidance will be developed by the Committee. The guidance will set out how the substance will be prescribed, prepared and dispensed in such a way as to ensure:
 - a. a minimal number of individuals handle the substance
 - b. there is a clear chain of command and clear documentation
 - c. the substance is always held securely.
- 433. The law will provide that the Jersey General Hospital (JGH) Pharmacy will compound, store, pack and dispense substances used for the assisted dying substance. No other pharmacy will be permitted to do so.
- 434. Pharmacy Professionals involved in the preparation of the substance must be registered with the Jersey Assisted Dying Service i.e., they must have 'opted -in' to undertaking activities that directly support assisted dying and have undertaken the mandatory assisted dying training. The substances used are anticipated to be substances that do not require specialist preparation and/or are substances that pharmacy professionals regularly dispense it is the dosage and combination of the substances that is specific to assisted dying and, as such

- there is no requirement for specific training on the preparation and dispensing of the substances.
- 435. JGH pharmacy staff will be able to conscientiously object to acting as dispensing pharmacists in relation to assisted dying, as this will constitute direct participation in the assisted dying.
- 436. The Administering Practitioner will prescribe the substance in most instances. Where this is not possible, for example if the designated Administering Practitioner is not registered as an independent prescriber, another involved practitioner will prescribe the substance (most usually the Coordinating Doctor). The JGH Pharmacy will hold a list of registered assisted dying practitioners who are also independent prescribing professionals.
- 437. The substance prescribed will vary depending on the agreed administration method (i.e., orally or via IV, see paragraph 465). In addition to prescribing the substance, the following will also be prescribed:
 - a. additional therapies for symptom control (e.g., anti-emetics to control vomiting and nausea; sedatives to control refractory systems such as pain and agitation)
 - b. back-up IV substances, both for those who choose oral medication and those who chose IV medication. In the event of any failure of administration (for example, the oral medication is dropped or spilt by the person before being ingested) or to be used in the event of medical complications (see paragraph 473)
- 438. When a person has approval for an assisted death and is in the process of completing the Assisted Death Care Plan, the Care Navigator will notify the Pharmacy, the notification will include details of who has been assigned as the Administering Practitioner and the intended date for the assisted death.
- 439. The Pharmacy Professional will only dispense the substance to the Administering Practitioner either at the JGH Pharmacy or, if agreed in advance, they may deliver to substance to the Administering Practitioner, for example, at the approved location of the assisted death.
- 440. When the substance is dispensed, both the Pharmacy Professional and the person collecting the substance (i.e., the Administering Practitioner) must complete and sign the Assisted Dying Substance Dispensing form, the details of which will be prescribed by Order of the Minister.
- 441. This form will record details of the assisted dying substance and administering products (for example the IV kit) that are dispensed.
- 442. The substance will be dispensed in a sealed and individually numbered box, clearly marked with a warning of its purpose i.e., "If ingested, this substance

- will cause death". Only the dispenser and Administering Practitioner will have access and authorisation to open the box with a code.
- 443. The Administering Practitioner must appropriately dispose of any unused assisted dying substance on site (for example if the assisted death took place in JGH or in care facility with appropriate disposal facilities) or returned to the JGH Pharmacy, if on-site disposal is not available. Disposal may be:
 - a. following an assisted death, or
 - b. in the event that the substance was dispensed but the person does not go through with the assisted death.
- 444. Disposal will be in accordance with specific procedures for the disposal of any controlled drugs, the details of which will be outlined in the Assisted Dying Substance Administration Guidance (see paragraph 455).

The assisted dying substance

- 445. The Authorised Drug Regimen for assisted dying will be approved by the Committee. The law will provide that the Committee, in the developing the regimen must consult any organisation or body that the Committee deems relevant, for example the General Pharmaceutical Council.
- 446. Jurisdictions which permit assisted dying generally do not provide information about the drugs / drug combinations deployed. For obvious reasons, they do not want information about the drugs and dosage to be readily available in the public domain. It is known, however, that different jurisdictions will use different drugs / drug combinations with the variations in approach being driven by factors such as the availability of certain drugs in those jurisdictions and the permitted methods of assisted dying (oral administration vs. IV administration).
- 447. The Canadian assisted dying drugs protocol is a matter of public record where the combination and types of medications most commonly used for IV administration is:
 - an anxiolytic (sometimes called anti-anxiety medications or tranquilizers) this has the effect of relaxing the person, and they begin to lose
 consciousness
 - b. an anaesthetic this second drug puts the person into a deep coma
 - c. a neuromuscular blocker the third drug stops their breathing and heart, and results in death⁴¹ ⁴²

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⁴¹ IV protocol- final (camapcanada.ca)

FAQ – CAMAP (camapcanada.ca)

- 448. The majority of drugs used for the purpose of assisted dying in other jurisdictions are either commonly prescribed or are controlled drugs that are currently used in Jersey for other purposes and at different dosages.
- For the purpose of assisted dying, however, the drugs used would likely involve 449. unlicensed (or 'off-label') prescribing, meaning that the person prescribing the medicine intends to use it in a different way than that stated in its licence. This is because the drugs have not undergone clinical trials for the purpose of bringing about a person's death. 'Off label prescribing' is a recognised practice in other areas of healthcare. If a professional wants to prescribe an unlicensed medicine, or a licensed medicine off-label, they must follow their professional guidance, for example the General Medical Council's good medical practice guidelines. These include giving information about the treatment and discussing the possible benefits and harms so that the person has enough information to decide whether or not to have the treatment - in this instance that the assisted dying substance would cause the person's death and discussion of any possible medical complications during the administration of the substance. This informed consent will be discussed at length with the Administering Practitioner, when completing Assisted Death Care Plan. 43
- 450. Whilst drugs used in assisted dying elsewhere have not undergone clinical trials for that purpose, there have been a number of studies and reviews been undertaken to better understand the efficacy and safety of the drugs used as the assisted dying substance.

Step 7: Assisted death

- 451. The Administering Practitioner will arrive at the agreed location, on the agreed date and time, to support the administration of the assisted dying substance.
- 452. The law will provide that if the assisted death takes place in a private residence, the Administering Practitioner must be accompanied by another professional (most usually, another member of the Assisted Dying Service for example the Care Navigator or a registered nurse from the MDT) who will act as witness to the administration of the substance ("administration witness").
- 453. If the professional accompanying the Administer Practitioner is the Care Navigator they may:
 - a. act as the administration witness, and
 - b. provide practical and emotional support to the person and any family or loved ones who are present
- 454. If the professional accompanying the Administering Practitioner is a registered nurse or a doctor, in addition to the duties outlined in paragraph 453 above, they

⁴³ Information for the public on medicines | Making decisions about your care | NICE and the public | NICE Communities | About | NICE

- may also provide clinical support under the direction of the Administering Practitioner, for example, setting up IV tubes and preparing the substance.
- 455. Detailed Assisted Dying Substance Administration Guidance will be developed by the Committee, which will outline these duties.
- 456. If the assisted death is to take place in the Jersey General Hospital, the Administering Practitioner may be supported by a doctor or registered nurse who has not opted-in as an assisted dying practitioner (but who does not conscientiously object to supporting the Administering Practitioner).
- 457. On arrival the Administering Practitioner will:
 - a. record who will be present during the assisted death, as this may have been subject to change since the Assisted Death Care Plan was developed (for example, some family members who previously declined to attend may have subsequently changed their mind)
 - b. re-confirm the roles and responsibilities of all present
 - c. re-confirm the mode of assisted death and the anticipated process, including what will happen immediately after the person dies
 - d. check what consents are in place, for example a Waiver of Final Confirmation of Consent and an ADRT/ DNACPR (see after paragraph 426)
 - e. undertake the final review.

Final Review

- 458. Immediately prior to the administration of the substance, the Administering Practitioner will carry out a final review to determine if they are satisfied that the person has decision-making capacity.
- 459. If it is determined that the person has decision-making capacity, the Administrating Practitioner will then assess whether the person:
 - a. continues to have a voluntary, clear, settled and informed wish to proceed.
 If the Administrating Practitioner determines this is not the case the process must stop; and
 - b. is giving their final confirmation of consent (or is withdrawing their consent). If the person does not provide their final confirmation of consent or is withdrawing their consent the process will stop. (Note: a Step Transition form is not required at this point in the process as it is replaced with a Final Consent and Review form)

- 460. If the Administrating Practitioner determines that the person does not have decision-making capacity, the administrating practitioner will stop the process, unless the person made a Waiver of Final Confirmation of Consent (Route 1 only).
- 461. As set out in Waiver of Final Confirmation of Consent, after paragraph 426, even if the person has made a Waiver of Final Confirmation of Consent, the process will not proceed if, as this point, the person demonstrates a refusal or resistance to the administration of the substance.
- 462. The Administering Practitioner will document all final checks on the Final Consent and Review form, which will prescribed by Order of the Minister, and will record details of their final review of the person, including:
 - a. record final consent from the person prior to commencing with the administration of the assisted dying substance
 - b. reconfirm person is making the request in a voluntary, clear, settled and informed manner
 - c. reconfirm that the person has decision making capacity and ensuring that a Wavier of Final Confirmation of Consent is in place if the person has lost their capacity
 - d. check what advance consents are in place, for example DNACPR
- 463. Copies of the Final Consent and Review form must be submitted to the Assisted Dying Review Panel along with all other documentation held on the person's assisted dying record, and this should be done within 2 working days of the person's death. For all Route 2 deaths, the Administering Practitioner must also notify the Tribunal of the assisted death within 2 working days, so that their documentation can be provided to the Assisted Dying Review Panel.
- 464. Once the final review has been completed the Administering Practitioner may begin administration of the assisted dying substance.

Methods for administration of an assisted death

- 465. There are four modes of administration, the mode of administration will have been agreed in advance between the person and the Administering Practitioner. The four modes are:
 - a. self-administration oral or by a percutaneous endoscopic gastrostomy (PEG) or nasogastric tube (NG)
 - b. self-administration intravenous delivery, triggered by the person
 - c. practitioner administration IV injection

- d. practitioner administration orally, including by a percutaneous endoscopic gastrostomy (PEG) or nasogastric tube (NG).
- 466. When the person has chosen <u>self-administration</u>, the Administering Practitioner will:
 - a. prepare the substance and remind the person how the substance should be taken (this will have been previously discussed)
 - b. stay with or nearby the person, as the person wishes, whilst the person takes the substance and up until the person dies (they do not have to be in the same room, but they must remain close by)
 - c. check and confirm the death
 - d. as soon as practicably possible, remove any items related to the substance, such as IV lines or feeding tubes, and remove these for safe disposal, or return to the General Hospital Pharmacy, along with any unused substance.
- 467. The law will provide that where the person has chosen to self-administer the substance, a family member or loved one may support them in the process, for example supporting the person to bring the cup to their lips. This would likely be an extension of the care and support that loved ones have been providing over the previous days and weeks. However, this may only be done under the direction of the Administering Practitioner.
- 468. Detailed Assisted Dying Substance Administration Guidance will be provided in the prescription and administration protocols which will be agreed by the Committee. Detail on support to self-administer will also be covered within the professional training modules.
- 469. The administration witness will be required to certify on the post-death administration form (see paragraph 479) that they witnessed the Administering Practitioner providing the assisted dying substance to the person and they witnessed the person self-administering the substance.
- 470. When a person has chosen <u>practitioner administration</u>, the Administering Practitioner will:
 - a. prepare and administer the substance
 - b. stay with or nearby the person, as the person wishes, until they die (they do not have to be in the same room, but they must remain close by)
 - c. check and confirm the death
 - d. as soon as practicably possible, remove any items related to the substance, such as IV lines or feeding tubes, and remove these for safe disposal, or

return to the General Hospital Pharmacy, along with any unused substance.

- 471. The law will provide that, whilst other professionals may assist the Administering Practitioner with the process, for example, setting up IV tubes and preparing the substance, the only persons authorised in law to administer the substance will be:
 - a. the Administering Practitioner, or
 - b. the person, with or without the assistance of a loved one.
- 472. The administration witness will be required to certify that they witnessed the Administering Practitioner administer the assisted dying substance to the person (this will be recorded on the post-death administration form).

Complications with administration of the assisted dying substance

- 473. As part of the Assisted Dying Substance Administration Guidance, detailed protocols will be developed to cover the occurrence of a medical complication.
- 474. Administration complications could include the person taking longer to die than expected or issues with the administration of the substance (for example regurgitation and vomiting, or seizure). In most cases it is anticipated that the person will have:
 - a. made an advance decision to refuse treatment which would prevent medical staff from attempting resuscitation
 - b. provided confirmation of consent to proceed, which would permit the Administering Practitioner to administer the assisted dying substance via IV if the oral mode fails.
- 475. In Western Australia, for example, 2.7% of assisted deaths in 2021-22 reported complications. All complications related to practitioner-assisted oral ingestion and involved regurgitation/vomiting, coughing or an extended length of time for the substance to take effect.⁴⁴
- 476. Where there are complications with oral administration of the substance, the Administering Practitioner:
 - a. may move to IV administration:
 - with consent of the person if they still have decision-making capacity at that point, or
 - where there is a consent to proceed in place, even where the person has lost decision making capacity

⁴⁴ Voluntary Assisted Dying Board Western Australia Annual Report 2021-22 (health.wa.gov.au)

- b. will not be able to move to IV administration where the person has lost capacity and there is no consent to proceed in place. In these circumstances the Administrating Practitioner can do no more than provide the person with suitable treatment to ensure they are comfortable, for example administering oxygen. It is possible, albeit extremely unlikely, that the person may require transfer to hospital in these circumstances.
- 477. In the highly unlikely event that there is also no Advanced Decision to Refuse Treatment in place, and the person has lost the capacity to refuse treatment at this point in time, the Administering Practitioner (and/or hospital staff) may need to attempt life sustaining measures but only if it were deemed appropriate to do so (i.e. the life sustaining measures is likely to be successful and it would not cause additional harm to the person). The Administering Practitioner (and/or hospital staff) would also need to consider if it were in the person's best interest which would generally be considered unlikely given that it is directly contradicts their assisted dying request.
- 478. Further detail will be covered in the Assisted Dying Substance Administration Guidance.

Step 8: After an assisted death

- 479. Once the Administering Practitioner has confirmed the death of the person, they must complete a Post-Assisted Death Administration form, the details of which will be prescribed by Order, recording:
 - a. who was present at the death
 - b. the administration witness' declaration of witnessing the administration of the substance
 - c. the time of the administration of the substance
 - d. the time of death
 - e. dosage and substances used
 - f. details of the administration process including any support provided by loved ones or any intervention made by them
 - g. details of any complications that may have arisen relating to the administration of the substance
 - h. confirmation of medical eligibility i.e. 'Route 1' or 'Route 2' and the physical medical condition(s) that made them eligible (details related to medical eligibility are set out in the form so that the Registered Medical Practitioner who is completing the Medical Certificate of Fact and Cause of Death has this information readily available)

480. The form must be signed by the Administering Practitioner, with the administration witness signing their declaration. Copies of the signed Post-Assisted Death Administration form must be submitted to the Assisted Dying Review Panel (see paragraph 501) and this should be done within 2 working days of the death.

Death Certification

- 481. In addition to the Post-Assisted Death Administration form, a Medical Certificate of Fact and Cause of Death ("MCFCD") must be completed in the same way as all other deaths in Jersey, as required under Article 64 of the Marriage and Civil Status (Jersey) Law 20011 ("the 2001 Law"). The certificate given under Article 64 must be provided to the relevant registrar within the period of 5 days following the death. A relevant registrar can be either a Parish Registrar or the Superintendent Registrar, dependent upon if the parish has a registrar in post at the time of the assisted death.
- 482. An MCFCD is usually completed by a qualified registered medical practitioner (RMP) who is qualified in relation to the death. A medical practitioner is qualified if they have attended to the deceased during their last illness and within the 14 days prior to their death. If no doctor is qualified in relation to a death, the 2001 Law requires that the Viscount is notified. The Viscount may, after further enquiries, authorise an unqualified registered medical practitioner to complete the certificate, i.e., someone who did not attend to the deceased within the 14 days prior to their death.
- 483. All assisted deaths will be certified by the dedicated assisted dying RMP service which will consist of medical practitioners who have had specific training on death certification for assisted deaths. The law will provide that the assisted dying RMP practitioners ("ADRMP"):
 - a. may not be employed as an assisted dying practitioner by the Jersey Assisted Dying Service; and
 - b. may not have a personal or professional relationship with the Administering Practitioner for example, they could not be related to each other, or employed within the same GP practice.
- 484. Any ADRMP must have attended the person within the 14 days prior to their death as required by Article 64(2)(a) of the 2001 Law so that they are qualified in relation to that person's death (see paragraph 427). The Administering Practitioner must ensure this has happened either before or during Step 6 'Assisted Death Care Planning'.
- 485. As soon as practicably possible after the death, the Administering Practitioner must notify the ADRMP of the death and must provide to them the signed and dated copies of the:

- a. Final Consent and Review form
- b. Post-Assisted Death Administration form.
- 486. The ADRMP will then examine the body, review the Final Consent and Review Form, and Post-Assisted Death Administration Form, the person's medical notes and history and complete the MCFCD in a similar way to any other death that occurs. This completed MCFCD can then be provided to the "informant" who will inform the relevant registrar of the death ("the informant"- an informant is the person required under the 2001 Law to inform the relevant registrar of a death within 5 days of the death occurring. This could be for example, a family member if they wish to inform the Registrar.)
- 487. It is proposed that an assisted dying death would not have to be reported to the Police or Viscount as a matter of course, other than where the death was not in accordance with, or suspected not to be in accordance, with assisted dying legislation.
- 488. Therefore, Article 65(c) of the 2001 Law will require amendment so that the duty placed on a relevant registrar to notify the Viscount of a death which is "believed to be unnatural", is altered so that it is expressly clear that this duty is not triggered by an assisted death.
- 489. Article 65(c) currently sets out:

"Where the relevant registrar is informed of the death of any person he or she shall, as soon as practicable, notify the Viscount of the death if the death is one which the relevant registrar has reason to believe to have been unnatural or to have been caused by neglect or any unlawful act or to have been attended by suspicious circumstances."

- 490. An amendment is required to Article 65(c) to disapply the duty placed on the relevant registrar to notify the Viscount if the relevant registrar has reason to believe to have been unnatural where that death is an assisted death.
- 491. Furthermore, an amendment is required to Article 65(e) is also required so that the relevant registrar is not required to notify the Viscount if the death appears to have occurred during a 'medical procedure' provided that death was an assisted death. Article 65(e) currently sets out:

"Where the relevant registrar is informed of the death of any person he or she shall, as soon as practicable, notify the Viscount of the death if the death is one which appears to the relevant registrar to have occurred during a surgical operation or other medical procedure or before recovery from the effect of an anaesthetic."

492. Amendments will also be required to the Inquests and Post-Mortem Examinations (Jersey) Law 1995 ("the 1995 Law") to clarify that Article 2(1)(c) of the 1995 Law does not apply to properly conducted assisted deaths, and would therefore expressly exempt deaths brought about by assisted dying to ensure that assisted deaths would not result in automatic involvement of the

Viscount. However, any person would still be able to report a death where they have reason to believe that a deceased person died as a result of violence or misadventure, as a result of negligence or misconduct or malpractice on the part of others, or under such circumstances as may require investigation as per Article 2(1) of the current investigation.

- 493. Article 2(4)(b) of the 1995 Law currently sets out that when someone dies in a home provided by a care home service, as defined in paragraph 4 of Schedule 1 of the Regulation of Care (Jersey) Law 2014, that the care home manager or the person in charge of the home must immediately notify a police officer of the facts and circumstances relating to the death. The police officer in turn must, as soon as reasonably practicable, notify the Viscount of those facts and circumstances. It is proposed to disapply this requirement where an assisted death takes place in a care home service, so that the manager or person in charge is not required to notify a police officer.
- 494. An assisted death will be recorded in the same way as other deaths in Jersey. This means that the MCFCD would record:
 - 1.(a) the disease or condition leading to the death
 - 1.(b) any antecedent causes
 - 1.(c) any morbid conditions underlying last conditions
 - 2. any other significant conditions that contributed to the death but not related to the disease or condition causing the death.
- 495. In the case of an assisted death, an example of how and MCFCD would be completed would be as follows:
 - 1.(a) the disease or condition leading to the death: cardiorespiratory arrest
 - 1.(b) any antecedent causes:
 - administration of assisted dying substance
 - 1.(c) any morbid conditions underlying last conditions:

metastatic pancreatic cancer

2. any other significant conditions that contributed to the death but not related to the disease or condition causing the death.

none

496. A relevant registrar is responsible for registering deaths in accordance with the 2001 Law. Every register of death is publicly available. Each entry details the cause of death of a person as entered into the register using the particulars

provided in the MCFCD – i.e. the causes listed in 1a, b and c and 2, as detailed in above.

497. For the purposes of clarity, assisted deaths will not be recorded as suicide because they are not suicide. This is the case in all other jurisdictions where assisted dying is legal.

Burial / cremation

498. The process for burial or cremation of a person who has had an assisted death would be the same as other deaths in Jersey. For cremations this includes an additional independent examination of the body of the deceased person, which is a requirement for all bodies that are to be cremated as per the Cremation (Jersey) Law 1953 ("the 1953 Law") and the Cremation (Jersey) Regulations 1961 ("the 1961 Regulations"). The law requires amendment so that that the ADRMP who completes the certificate of application for cremation must not be either personally related or professionally connected to either the Administering Practitioner in the case of an assisted death, or, the ADRMP who completed the MCFCD, as this is currently forbidden by Law.

Note: Organ donation

Post-assisted death organ donation is permitted in some jurisdictions where assisted dying is legal - including Australia, Belgium, the Netherlands, Canada and Spain.

It will also be permitted in law in Jersey.

Organ donation in Jersey and the issue of consent to donation is governed by the Human Transplantation and Anatomy (Jersey) Law 2018. The law works on an 'opt out' basis – a person in Jersey is considered to have agreed to be an organ donor when they die (deemed consent) unless they have opted out and made the decision not to donate.

The assisted dying law will not prohibit post-assisted death organ donation in Jersey, but guidance will be developed by the Committee (Assisted Dying and Organ Donation Guidance) which will provide guidance on:

- a. discussions with the person prior to their death
- b. if the person does wish to donate their organs, this will include discussion with the NHS Organ Donor Register
- c. discussions with family members before and after the assisted death (as is standard for all organ donations)
- d. practical considerations and procedures for donating organs following an assisted death.

Some of the diseases and conditions that make a person eligible for an assisted death, such as cancer, rule out the possibility of donation as the organs are no longer viable.

Others including neurodegenerative conditions such as Motor Neurone Disease (MND) may allow for organ donation after an assisted death.

Organ donation may also not be possible where the place of death is not in a hospital, although some jurisdictions, for example, the Netherlands will transfer the deceased to hospital to allow for donation.⁴⁵

Section 10: Regulation and oversight

499. The Jersey Assisted Dying service:

Page - 138

⁴⁵ Organ donation after medical assistance in dying at home - PMC (nih.gov)

- a. must operate within the law and be seen to do so
- b. must be safe, and
- c. protect and safeguard people who may be vulnerable to coercion and control
- d. accord with the highest standards of clinical safety
- e. must meet the needs of care receivers and their families (be person-centred)
- f. must be of high quality, and
- g. must be well-organised and easy to navigate.
- 500. Appropriate structures / systems will be put in place to ensure the safety, quality and effective delivery of the service, and to provide public assurance of these matters. These structures will include:
 - a. an Assisted Dying Assurance and Delivery Committee (see paragraph 72)
 - b. an Assisted Dying Review Panel to undertake a post-death review of each individual assisted death
 - c. independent regulatory oversight by the Jersey Care Commission.

Service provision and assurance

a. As set out in Section 4 the law will provide that an HCS Assisted Dying Assurance and Delivery Committee will be formed to establish and oversee the Jersey Assisted Dying Service, including ensuring robust clinical governance of this service etc.

Assisted Dying Review Panel: post-death review

- 501. The law will state that a post-death review must be carried out after each assisted death by the Assisted Dying Review Panel ("the Panel"). This will be an administrative review.
- 502. The purpose of the post-death review is to:

- a. determine whether, in each case, there was proper adherence to the legislation and guidance
- b. identify any process matters that may require improvement / change.
- 503. The Panel will be established by the Committee and will report to the Committee. The Panel must operate in accordance with its terms of reference. The Committee will develop the Panel's terms of reference for approval / amendment by the Minister. The terms of reference must be adopted by Ministerial decision and must be published.
- 504. The law will require that the Committee, in developing the terms of reference, must consult the Jersey Care Commission and any other persons that the Committee or the Minster deems appropriate.
- 505. The law will provide that the terms of reference must set out:
 - a. the function of the Panel (i.e., to undertake a post-death administrative review to determine whether, in each case, there was proper adherence to the legislation and guidance)
 - b. processes for delivery of those functions
 - c. arrangements for appointment and removal of Panel membership, including the maximum and minimum number of members.

Post-death review

- 506. As set out above, the purpose of the post-death review is to:
 - a. determine whether, in each case, there was proper adherence to the assisted dying legislation and guidance
 - b. identify any process matters that may require improvement / change.
- 507. The Panel will, in each case, review all relevant documentation from Steps 1 to 8 of the assisted dying process (which will from part of the person's Assisted Dying Record) and any relevant documentation related to the findings of a tribunal process (if relevant) or an appeals process (if relevant). This will include but is not limited to, review of:
 - a. referral documentation
 - b. First Formal Request form

- c. all Declaration of Interest forms signed by all involved professionals and the Care Navigator
- d. all Step Transition forms and Assessing Doctor Transfer forms
- e. First Assessment Report form
- f. Independent Assessment Report form
- g. any Second Opinion Assessment Report forms
- h. Second Formal Request form
- i. Co-ordinating Doctor Administrative Review (approve or decline) form
- j. record of approval or decline by Tribunal [Route 2 only]
- k. records of any appeals
- any other supporting or relevant documentation, including additional assessments or advice and opinions that formed part of either the first or independent or second opinion assessments
- m. Final Consent and Review form
- n. Post-Assisted Death Administration form
- o. all formal documentation and decisions produced by the Tribunal (Route 2 only).
- 508. Following an initial review of documentation, the Panel will determine whether they are:
 - a. satisfied there was adherence to the legislation and guidance, or

- b. whether additional information or investigation is required to determine adherence to the legislation and guidance, or
- c. not satisfied that there was adherence to the legislation and guidance.
- 509. If the Panel is satisfied there was adherence to the legislation and guidance, the Panel will submit a report to the Committee setting out its findings. The report may include any recommendations for improvement that the Panel deem appropriate (i.e., the Panel may find that all practice accorded with legislation and guidance but in so doing may have identified potential process improvements).
- 510. If the Panel determines they require additional information or that further investigation is required, they may request that additional information is provided to them in writing or in person (which may include attendance at a Panel meeting). Including by any of the following:
 - a. any involved professional, and / or
 - b. the Care Navigator and / or
 - c. any professional who provided a supporting opinion or assessment and / or
 - d. the Tribunal (where relevant).
- 511. The law will provide that any involved professional, the Care Navigator and any professional who provided a supporting opinion or assessment must provide to the Panel the information requested, whether in writing or in person.
- 512. Following dialogue (where relevant) and review of the additional information the Panel will either determine that they are:
 - a. satisfied there was adherence to the legislation and guidance, or
 - b. not satisfied that there was adherence to the legislation and guidance.
- 513. The Panel will submit a report to the Committee setting out its findings. This will include any action(s) that the Panel recommends the Committee should take to address the Panel's findings. These actions may include, for example, recommending to the Committee:

- a. potential safety and quality improvements or process changes for consideration by the Committee (including proposed changes to guidance, practice and forms)
- b. to refer matters which the Panel believes should be referred to a relevant person or body, for example, HCS as the employer / contracting body for involved professionals, the Coroner, the States of Jersey Police, the Superintendent Registrar, the relevant professional lead (for example, the Chief Pharmacist or Chief Nurse; Safeguarding Partnership Board)
- c. whether further investigation may be required by HCS as the employer / contracting body for involved professionals. (This to include whether an assisted dying practitioner is suspended from the Assisted Dying Register pending a full investigation of their practice and whether this investigation is undertaken by HCS as the employer / contracting body for involved professionals, the JCC, a relevant UK professional regulatory body or another relevant body).

514. In all cases:

- a. the Panel must set out the reasons for making that recommendation to the Committee
- b. the Committee must give due consideration to the Panel's findings and recommendations
- c. the Committee may adopt or reject the Panel's recommendations, or take any alternative course of action that the Committee believes to be best course of action
- d. the Committee, having considered the Panel's finding and determined what, if any action to take, will provide a copy of the Panel's findings report to the JCC and details of any action to be taken.

Panel procedures

- 515. The Committee must establish the Panel in such as time as to ensure that the post-death administrative review can be completed within 6 weeks of the death, or within 12 weeks where the Panel requires additional information from involved professionals and / or the Care Navigator and / or the Tribunal.
- 516. The Panel will meet on a monthly basis to review any completed assisted deaths that have taken place in the previous month.

517. In addition to undertaking a post-death administrative review for each assisted death, the law will provide that the Panel may undertake reviews of assisted death requests that did not progress to an assisted death, either because the person was assessed as ineligible, or the person withdrew from the process. The law will not specify the number of these reviews that must take place — and hence the number of Panels required — as it will be dependent on the numbers of requests received but the law will provide that Committee must be satisfied that sufficient reviews have been undertaken to provide the Committee with the necessary assurance.

Membership of Panel

- 518. The law will provide that the Panel members must be appointed by the Minister, on the recommendation of the Committee.
- 519. It is envisaged that the terms of reference will provide that the Committee will appoint up to 6 panel members, with at least 3 members attending each monthly panel meeting, although the number of Panel members may be amended by a decision of the Minister as the Minister deems necessary in light of the numbers of assisted deaths.
- 520. The Panel members will be experts in a range of related disciplines including:
 - a. legal expertise
 - b. end-of-life care specialists
 - c. medical ethicists
 - d. social care practitioners (including care for older people and people with disabilities)
 - e. medical practitioners with expertise in the types of terminal and nonterminal physical medical conditions that give rise to assisted dying requests, and
 - f. people with expertise in clinical service governance and safety.
- 521. Panel members may include Government of Jersey employees, including employees of the HCS Departments providing the Committee have determined that this does not represent a conflict.

522. The law will provide that the Minister may determine to remunerate the Panel members as the Minister deems appropriate.

Registration and inspection by the Jersey Care Commission

- 523. The law will provide that the Assisted Dying Service will be regulated and inspected by the Jersey Care Commission ("JCC"). This will require the Regulation of Care Law (Jersey) Law 2014 (the "2014 Law") to be amended to extend the Jersey Care Commission's remit to the Jersey Assisted Dying Service.
- 524. The 2014 Law provides a legislative framework for the independent regulation of health and social care in Jersey. It is underpinned by the Regulation of Care (Standards and Requirements) (Jersey) Regulations 2018 (the "2018 Regulations") which provides a detailed set of requirements that all regulated services must adhere to.⁴⁶
- 525. Schedule 1 to the 2014 Law will be amended to include the Jersey Assisted Dying Service as a defined regulated activity. Transitional arrangements will provide that the Jersey Assisted Dying Service may not operate until its provider and manager have registered with the JCC. To register the service, the JCC will require HCS to submit all the information the JCC deems necessary. This may include the JCC undertaking pre-registration visits (for example, to HCS pharmacy department to look at dispensing arrangements).
- 526. Regulations should be introduced under Article 3(7)(a) of the 2014 Law which set out that the registered provider of the Jersey Assisted Dying Service will be the Chief Officer of the Health and Community Services Department, who will have responsibility for ensuring that the Jersey Assisted Dying Service adheres to statutory requirements set out under the 2018 Regulations. In addition, the operational manager of the service will be required to register with the JCC (a decision as to who is designated as the operational manager will be determined at the point at which the law is approved and HCS commences service development).
- 527. The registration of the providers and managers of regulated activities is fundamental to the regulatory regime established by the 2014 Law. The regulatory regime requires the JCC to consider whether providers and managers, and the services they run are fit to be registered. Where a provider, manager or service is not fit or does not meet the regulatory standards required then this can be dealt with by the JCC applying conditions to registration, or potentially suspending or cancelling a service's registration. Providing a regulated activity without registration is an offence under Article 3(4) of the

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⁴⁶ Regulation of Care (Standards and Requirements) (Jersey) Regulations 2018

- 2014 Law. A provider who commits this offence is liable to imprisonment for a term of 12 months and to a fine.
- 528. Once registered with the JCC, Jersey Assisted Dying Service may commence operations. The Assisted Dying Assurance and Delivery Committee and the Service's registered manager must ensure that the Service acts in compliance with the statutory requirements which apply to all regulated health and social care services under Regulations 2 to 27 of the 2018 Regulations.
- 529. In addition, a new Regulation is required which is specific to the Jersey Assisted Dying Service. This should provide that the Service is required to discharge its statutory functions in accordance with the Law. A similar provision is provided in respect of social work services for children and young people under Regulation 77(2) of the 2018 Regulations. This is important as it will enable the JCC to regulate the Service fully, ensuring that it is compliant with all its statutory responsibilities as well as the general requirements placed on all services under Regulations 2 to 27 of the 2018 Regulations.
- 530. Furthermore, Regulation 29 will need to be amended to state that the JCC cannot stipulate that the assisted dying service must restrict its activities to particular categories of service user or particular age groups. These decisions will be for the Assembly.
- 531. Regulation 80 of the 2018 Regulations should be amended to ensure that the JCC must inspect the Jersey Assisted Dying Service at least once every 12 months to monitor and enforce compliance with both the 2018 Regulations and the new Assisted Dying Legislation. While the JCC must inspect the Service at least once per year, it may decide to inspect the service at any other time on either an announced or an unannounced basis. Article 26 of the 2014 Law provides the JCC with the power to enter any premises provided in connection with the provision of a regulated activity with or without the consent of registered providers or managers (excluding private dwellings, where consent is required).
- 532. In anticipation of the amendments to the 2014 Law coming into force, the JCC will develop, consult on and publish detailed standards setting out what providers must do to meet the requirements of the 2018 Regulations. This is provided for under Article 15 of the 2014 Law. These standards will provide the Jersey Assisted Dying Service with clear inspection guidance and will supplement the 2018 Regulations with further, specific requirements for the Service on how the JCC expects it to demonstrate compliance with the Law.

Acting on findings arising from inspections or from the Assisted Dying Review Panel

- 533. If the JCC finds that the Jersey Assisted Dying Service is failing to meet any of the requirements set out under the 2018 Regulations or its other statutory responsibilities, the JCC will take action in accordance with its existing escalation and enforcement policy and, in the first instance, is likely to issue the Service with an improvement notice.⁴⁷ Under Regulation 82(2) of the 2018 Regulations, this is a notice:
 - a. informing the registered person that these Regulations have been contravened;
 - b. specifying the time frame within which remedial action must be taken; and
 - c. explaining the consequences of a failure to take that remedial action.
- 534. Where the Service contravenes a requirement and fails to comply with an improvement notice, the JCC may refer this fact and relevant prosecution information to the Attorney General to decide whether to prosecute the registered provider and/or the registered manager of the Jersey Assisted Dying Service. A registered person who is found to have committed an offence is, under Regulation 82(5), liable to a fine of £50,000 for each breach of the Regulations.
- 535. Where the JCC finds that the registered manager of the Jersey Assisted Dying Service is not a fit person or has failed to comply with conditions or requirements imposed upon them, the JCC has the power to suspend their registration under Article 19 of the 2014 Law. The JCC may also cancel the manager's registration under Article 20(2) of the 2014 Law.
- 536. The ultimate sanction against services regulated under the 2014 Law is the cancellation of a service provider's registration with the JCC under Article 20 or Article 21 of the 2014 Law. This would, in effect, shut down the regulated service.
- 537. Article 22 of the Regulation of Care (Jersey) Law 2014 effectively provides that the JCC may cancel the registration of a service provider who fails to comply with conditions imposed on them by the JCC unless that service is an 'essential' service (i.e. a service for which a Minister is the sole provider). As the Jersey Assisted Dying Service would meet this definition of an essential service, the JCC could not cancel its registration but could escalate its concerns via a report to the Council of Ministers.

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 $^{^{47}}$ $\underline{\text{https://carecommission.je/wp-content/uploads/2022/03/Escalation-and-Enforcement-Policy-}\underline{002.pdf}$

- 538. However, it is proposed that, given the special nature of the Jersey Assisted Dying Service, Article 22(1) of the 2014 Law will be amended to provide that, even though the Minister will be the sole provider of the Service, it will fall outside of the definition of an 'essential service'. This will enable the JCC to cancel its registration if the JCC determines that there are grounds to do so.
- 539. To protect those who may have been approved for assisted dying but are yet to have been assisted to die, a new provision is required to ensure that these individuals will be unaffected by the cancellation of the Jersey Assisted Dying Service's registration under Articles 20 or 21 of the 2014 Law. This will establish that the effect of cancellation on the Service will be to prevent it from being able to assess and approve new patients to be assisted to die, but that those with existing approvals may still have an assisted death unless the JCC's grounds for cancellation rest with individual practice of either Coordinating Doctor and/or Independent Assessment Doctor of those specific persons.

540. In summary, the JCC:

- a. will act as a key consultee for the Committee when developing the assisted dying guidance and protocols listed at *Appendix 3: Forms and guidance*
- b. will develop detailed care standards against which the assisted dying service will be inspected
- c. will register both the manager and provider of the Jersey Assisted Dying Service which must happen before the service starts to operate
- d. will have the power to undertake announced or unannounced inspections which may include, for example, interviewing professionals, service users and, where appropriate their family and friends, reviewing care records and interrogating key service performance information
- e. must inspect the Jersey Assisted Dying Service at least once a year. The JCC may inspect all, or parts of the Service, more than once a year if the JCC deems it appropriate (whether announced or unannounced). The JCC must publish its inspection reports
- f. will receive notifications which it requires the Jersey Assisted Dying Service to provide. The JCC may decide to require the Service to notify it every time it assists a death and will require the Service to provide

notification of serious incidents. Notifications are required under Regulation 21 of the 2018 Regulations

g. will retain all relevant information provided by the Jersey Assisted Dying Service in relation to assisted dying assessments, in line with the JCC retention schedule for regulatory, oversight and reporting purposes.

Section 11: Offences

Suicide and assisting suicide in Jersey

- As matters currently stand there is a lack of clarity as to the legal provisions associated with suicide and assisting suicide in Jersey law.
- 542. Suicide was previously treated as a crime in Jersey under customary law but practice has evolved and the Courts have ceased treating suicide as a crime. The Homicide (Jersey) Law 1986 refers to the "offence" of "aiding, abetting, counselling or procuring a person's <u>suicide</u>" but it is doubtful whether that wording serves to create an offence, and whether there can be an offence of "aiding, abetting" etc. if suicide itself is no longer an offence.⁴⁸
- 543. Having consulted with the Attorney General, it is proposed this uncertainty is addressed at the same time as the introduction of an assisted dying law [which will set out a lawful process for assisted dying], to clarify that:
 - a. suicide (taking one's own life) is not an offence
 - b. an act capable of encouraging or assisting the suicide or attempted suicide of another person is an offence, if the act was intended to encourage or assist suicide or an attempt at suicide (i.e., encouraging or assisting another person to end their life in any way other than in accordance with the assisted dying law, would be an offence). Such an offence would be broadly in-line with section 2 of the UK's Suicide Act 1961⁴⁹.
- 544. Updating the law would have the benefit of creating an explicit offence for anyone who encourages or assists suicide in any other way for example buying lethal drugs for a partner with the intention that they will take them to end their life (this is an area of potential increased risk given the availability of some lethal drugs on-line, and associated prosecutions relating to supply of lethal drugs in jurisdictions such as Canada).
- 545. For the purposes of the law, an 'assisted death' will only relate to the death of a person who has requested, been assessed and approved for assisted dying and dies as a result of the self-administration or administration of an assisted dying substance, carried out in accordance with the law

Offences under the assisted dying law

546. In jurisdictions where assisted dying is permitted, there are two broad approaches to offences under the law:

Approach 1: assisted dying is treated in law as an exception to existing criminal offences such as homicide. This means that a medical practitioner who supports a person's assisted death would not be committing the offence of homicide if the assisted death complied with the assisted dying law, but would be committing homicide if the assisted death did not comply the assisted dying law.

⁴⁸ Homicide (Jersey) Law 1986 (jerseylaw.je)

⁴⁹ Suicide Act 1961 (legislation.gov.uk)

This is the approach in the Netherlands, Belgium and Luxembourg

Approach 2: this is similar to the first approach (i.e. outside of the assisted dying law, existing offences will apply), but also creates criminal offences for specific conduct under the assisted dying legislation. This is the approach used in most other jurisdictions, including Canada, New Zealand, all Australian states, and is the approach proposed for Jersey.

- 547. It is proposed that this approach is adopted in Jersey and the creation of additional offences is proportionate to the new roles and permissions created by an assisted dying law. It is an important safeguard, whereby the penalties act as a deterrent for any person who might intentionally act outside of the legislation.
- 548. It is proposed that the law will set out a number of offences for those who do not act in accordance with the law (as described in the table below). The offences would apply to any 'person' which could include professionals or, for example, family members.
- 549. Proposed offences within the assisted dying law are set out below. The offences will be subject to review, including by the Attorney General, during the law drafting phase of developing the proposals.

Offence	Details
Unauthorised	A person must not administer an assisted dying substance to
administration of assisted	another person unless the person is authorised to do so
dying substance	
Inducing a person to	A person must not, dishonestly or by coercion, induce
request, or revoke request	another person to make, or revoke (withdraw), a request for
for, assisted dying	access to assisted dying.
Inducing self-	A person must not, dishonestly or by coercion, induce
administration of voluntary	another person to self-administer an assisted dying substance
assisted dying substance	
Making a false or	A person must not make a statement in a form or other
misleading statement	document, or as part of the tribunal or appeal process as
	required to be made under the assisted dying law that the
	person knows to be false or misleading in a material
	particular.
Falsifying a document	A person must not knowingly falsify a form or other
	document required to be made under the assisted dying law.
Details of an assisted death	A person must not record or make public the details of an
not to be recorded or made	assisted death.
public	
	Details of an assisted death include:
	the method by which the assisted dying substance was administered

the name of the person who administered the assisted dying substance any other personal information related to the assisted death that is not publicly available

This does not apply if details of an assisted death are disclosed for a purpose under the assisted dying law or with the consent of the person to whom the personal information relates.

Failure to inform Jersey Assisted Dying Service of changes to professional registration or fitness to practise matter

An assisted dying practitioner must inform the Jersey Assisted Dying Service of any changes to their registration status with either their UK professional registration body, or the JCC, including:

- Any conditions or restrictions imposed on their registration, or the suspension or cancellation of their registration.
- b. Any arising fitness to practise issues that may impact on their registration with their UK professional regulatory body, the Jersey Care Commission or the Jersey Assisted Dying Service. They must do so within 7 days of being notified by any relevant person of a pending investigation of fitness to practise.

Table 1 – Proposed offences under the assisted dying law

- 550. A person will not commit an offence under the assisted dying law if the act is not carried out knowingly and the person has acted in good faith, having taken reasonable steps in accordance with the law and associated guidance. For example, if a Coordinating Doctor makes a determination that a person is making a voluntary request for assisted dying, but subsequent evidence comes to light to indicate that the request was made under coercion from a third party, then the Coordinating Doctor would not be committing an offence if they demonstrated that during the assessment process they took the required steps and had reasonable belief that the person was acting voluntarily.
- 551. [However, the third party may have potentially committed the offence of 'Inducing a person to request, or revoke request for, assisted dying' if the coercion is evidenced.]
- 552. The creation of specific offences in the assisted dying law will not affect the operation of existing criminal laws individuals who act outside the legal framework for assisted dying will still be subject to prosecution for offences such as homicide.

Professional conduct

- 553. In addition to the criminal offences outlined above, registered health and care practitioners may be subject to serious professional consequences if they participate in assisted dying and are non-compliant with:
 - a. the assisted dying law
 - b. registration requirements to act as an assisted dying professional
 - c. all policies, protocols and guidelines related to assisted dying
 - d. professional standards of the JCC and their UK professional regulatory body (GMC, NMC, GPhC, HCPC.)
 - including codes of ethics, codes of conduct and competency standards and including in relation to conscientious objection
- This could include investigations into their professional conduct by either their professional regulatory body, the JCC, their employer or a combination of these.

Privacy and confidentiality

- 555. The assisted dying law will protect the privacy of people accessing assisted dying, as well as the involved professional providing these services.
- As noted above, it will be an offence for any person to unlawfully record or make public information about an assisted death, including about the person accessing assisted dying or any health and care professional involved (whether or not they are an involved professional, a Care Navigator or professional providing an additional assessment or opinion).
- 557. This means a person must not record the details or publicly disclose the details by publishing or broadcasting the information in the media, through social media or any other source of communication that may be widely accessible.
- 558. However, it is not an offence to make a record or disclose personal information:
 - a. for a purpose under the assisted dying law, for example, where information is recorded in an approved form
 - b. if the person to whom the personal information relates gives consent to the information being recorded or disclosed
 - c. if a court or tribunal requires a person to produce documents or give evidence
 - d. if a person is authorised or required by law to record or disclose the information.



Section 12: Resource and financial implications, risks and next steps

Resource and financial implications

- 560. Implementation of assisted dying in Jersey, including the establishment of the Jersey Assisted Dying Service and all regulation and oversight mechanisms, will require the provision of additional funding within a future Government Plan.
- 561. Resources currently allocated for palliative care or associated services would not be re-directed to assisted dying and, as noted in paragraph 24iii, it is proposed that the assisted dying law should only come into force if the Assembly is satisfied that investment in end of life and palliative care is supporting improvements in the quality and availability of those services.
- 562. Evidence from other jurisdictions suggests that assisted dying could result in a cost neutral position (or cost savings) in overall health and care expenditure in the long-term. ⁵⁰ However, such an intent does not accord with the core principles of these assisted dying proposals [see section 2: Principles] and hence there has been no attempt to quantify any potential cost reductions in other areas of health and care spend in Jersey.
- 563. It should be noted that all costs set out below are indicative only. They are best estimates, based on currently available data. Updated cost estimates will be presented alongside the draft law. And may include recalculations, including of the following:
 - a. commercially sensitive elements such as the procurement of a bespoke training package for assisted dying practitioners and insurance costs
 - b. the exact drug combination used in the assisted dying substance
 - c. location of the Jersey Assisted Dying Service (i.e., the office from which the service operates).
- 564. In addition, it is important to note that there are numerous variables which means that the actual cost of delivery of the service will fluctuate on an annual basis dependent on factors such as:
 - a. numbers of annual requests for assisted dying in Jersey/ complexity of requests
 - b. variations in staffing costs and cost of assisted dying substance drugs
 - c. uptake and requirement for counselling, wellbeing and bereavement support

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⁵⁰ Cost analysis of medical assistance in dying in Canada - PMC (nih.gov)

- d. uptake and requirement for interpreting, communication support and advocacy
- e. regulatory action and appeals
- 565. Furthermore, as there is so little publicly available data related to the costs of assisted dying in jurisdictions where it is permitted, it needs to be recognised that there is potential for unknown additional costs.

Implementation and one-off costs

- 566. Key elements of set-up costs include:
 - a. project management of implementation
 - b. public information on assisted dying (webpage etc.)
 - c. information management (development of assisted dying record keeping system)
 - d. consultation and development of all forms, guidance and protocols (see Appendix 3: Forms and guidance)
 - e. establishment of, and initial recruitment costs related to:
 - Jersey Assisted Dying Service
 - HCS Assurance and Delivery Committee
 - Assisted Dying Review Panel
 - Assisted Dying Tribunal
 - f. initial recruitment costs and training of assisted dying practitioners and awareness training for all health and care staff
- 567. The estimated one-off implementation costs include

Category	Cost (£)
Implementation	363,607
Training	340,000
Information management	5,000
Jersey Assisted Dying Service	155,000
Public information	42,360
Regulation, oversight, approval	112,192
TOTAL	£1,018,159

Ongoing, annual costs

- 568. Some of the estimated ongoing costs associated with the introduction of assisted dying in Jersey are fixed, others vary dependent on the number of requests and assisted deaths per year.
- 569. The estimated fixed costs include, for example:
 - a. running costs of the Jersey Assisted Dying Service (core staff, facilities etc.)
 - b. oversight and regulatory costs, including ongoing costs for:
 - o HCS Assurance and Delivery Committee
 - Assisted Dying Review Panel
 - o Assisted Dying Tribunal

Estimating the number of assisted deaths in Jersey

- 570. It is not possible to make detailed projections of the number of assisted deaths per year in Jersey, given the variations in both:
 - a. demographic and societal make-up of the comparative jurisdictions; and
 - b. key provisions of different assisted dying legislation, including eligibility criteria
- 571. Therefore, estimated numbers for assisted deaths should be regarded with caution. Broad estimates of the number of assisted deaths per year in Jersey are outlined below.⁵¹ These are based on the latest available data on assisted deaths in Oregon, Western Australia, and Canada.⁵² In addition, the table provides a 'mid-point' between Canada and Western Australia given that Jersey's proposals broadly resemble a combination of the process and eligibility criteria in these two jurisdictions.

Jurisdiction	% of all deaths in that jurisdiction that are assisted deaths	Estimated annual assisted deaths in Jersey (numbers of people)
Oregon	0.6	6
Western Australia	1.4	13
Canada	4.1	38
Mid-point between:	2.75	25
Western Australia and		
Canada		

Staffing cost per assisted death

Western Australia: Voluntary Assisted Dying Board Western Australia Annual Report 2022-23 (health.wa.gov.au)

Canada: Fourth annual report on Medical Assistance in Dying in Canada 2022 - Canada.ca

⁵¹Based on 2022 total annual death figure in Jersey: <u>Jersey Mortality Report 2022 (gov.je)</u>

⁵² Oregon: <u>DWDA 2022 Data Summary Report (oregon.gov)</u>

- 572. The estimated staffing cost per assisted death includes all assisted dying practitioners involved in the assessment process (assessing doctors and MDT staff), health and care professionals providing supporting assessments or opinion, Pharmacy Professionals, the Administering Practitioner and the assisted dying RMPs to certify the death. They do not include estimated costs for appeals to assisted dying decisions.
- 573. These staffing costs are intended as an average and it is anticipated that some, more straightforward requests for assisted dying will incur less staffing costs and complex cases, in particular 'Route 2' requests, may incur more staffing costs.
- 574. These costs are based on an estimated average assessment times and do not take into account specific contractual arrangements, or the potential for staff being engaged by the Jersey Assisted Dying Service, but not deployed, dependent on the number of requests for assisted dying.
- 575. The estimated average staffing cost per assisted death is £23,601.
- 576. This cost does not include other costs (fixed costs, regardless of the number of assisted deaths per year such as ongoing regulatory and oversight costs and other costs, such as the cost of the assisted dying substance. This is estimated at a fixed cost per year of £506,208)

Cost estimate per assisted death and as an annual total

577. Table 4, below, provides total cost estimates both per assisted death and as an annual cost, for a range of total assisted deaths per year, based on the estimated number of annual assisted deaths set out in paragraph 571, above:

Number of assisted deaths per year	-	assisted death (staffing ixed costs)		ongoing cost for assisted dying y (based on no. of assisted deaths
6	£	107,969	£	647,814
13	£	62,540	£	813,020
25	£	43,849	£	1,096,225
38	£	36,922	£	1,403,036

Risks

- 578. The risk list set out below describes, at a high-level, some of the key risks associated with the development of assisted dying legislation, the establishment and ongoing delivery of an assisted dying service and the impact of permitting assisted dying in Jersey. The risks include those related to:
 - a. **individual rights** risks that may impact the rights of individuals
 - b. **safeguarding** ensuring sufficient safeguards for patients and professionals within the assisted dying process
 - c. **medical malpractice** risks of malpractice where protocols and safeguards are not adhered to, or where medication or the process fails

- d. **reputational** to Jersey as a jurisdiction and / or the Government of Jersey
- e. **professional** risks to professionals either engaged by Jersey Assisted Dying Service or undertaking assessments, or other on-island health and care professionals
- f. **financial** financial impact on individuals, professionals or Government of Jersey
- g. **societal** risks related to changes in public perception of the value of life for older people, people with disabilities or life limiting conditions or people requiring palliative or end of life care
- h. **legal** risk of legal challenges.
- 579. A summary of the risks identified to date, and potential response, controls or mitigations are outlined below:

	Risk outline	Response, mitigation or control
1.	The introduction of a legal framework for assisted dying in Jersey may impact wider societal attitudes towards people who are disabled, ill or require care and treatment. This could include:	Continued consultation during law drafting process with key groups including health and care professionals and disabled Islanders (building on consultation undertaken to date)
	 wider society dismissing / failing to recognise the value of those people's lives individual people perceiving their lives having diminished value / perceiving themselves as a burden 	Policy principles set out that: • assisted dying will not replace investment in the palliative care and end-of-life care services which provide for people who require care and treatment
		• it is envisaged that the draft law to be presented to the Assembly will ask Members to agree, in principle, that legislation should not be brought into force until the Assembly is satisfied that decision taken in the 2023 to provide for additional investment in end of life and palliative care is supporting improvements in quality and availability of those services.
		Assisted dying law will set out that a person may only be eligible for assisted dying if they have a voluntary, settled and informed wish to do so.
2.	A lobby group / individual may challenge decision of Jersey to permit assisted dying in European Court of Human Rights (ECHR).	Work has been undertaken with Law Officers Department to ensure development of proposals aligns with European Convention on Human Rights and with key international conventions including UNCRC (United Nations Convention on the Rights of

If the law does not take account of requirements of international conventions which are extended to Jersey (e.g. UNCRC) there is potential reputational damage and associated civil action.

the Child) and UNCRPD (United Nations Convention on the Rights of Persons with Disabilities).

3. The report and proposition is constructed to provide multiple safeguards that work to protect both people requesting an assisted death and wider society.

Throughout development of draft law, continue consideration of issues under international human rights frameworks.

Lobbying of States Members prior to States Assembly debate may result in amendment / removal of key safeguards.

Continue engagement with public, lobby groups and States Members to support understanding of safeguards and impact of potential amendment or removal, during lodging period.

4. If the safeguards established in the law do not work effectively or the safeguarding processes are not robust enough, a person who does not meet the eligibility criteria may have an assisted death (for example a person who has been subject to coercion or who does not have decision-making capacity).

Proposals detail two stage assessment process with registered, specially training docotrs to ensure compliance with eligibility safeguards (plus legal requirement to seek supporting assessment / opinions where assessing doctors are not satisfied that eligibility criteria has been met).

Primary implications:

• loss of life

Multidisciplinary team will:

Secondary implications:

- distress to family / friends
- reputational damage
- criminal prosecution and civil action for damages.
- support robust assessment of eligibility criteria as assessing doctors will benefit from different professional perspectives / challenge
- undertake supporting assessments, were required (particularly in relation to assessment of family dynamics to support detection of coercion)

Assurance and Delivery Committee required to monitor and ensure compliance with standards and process.

Professional standards. All assisted dying practitioners:

- must be registered with the Assisted Dying Service
- are required to meet professional competencies
- are required to have undertaken mandatory training (with 3-year refreshment)

		Systems in place to support identification of systemic risks / failings including: • Assisted Dying Review Panel to review all assisted deaths, immediately after that death • registration and inspection of Assisted Dying Service by Jersey Care Commission
5.	Limitations of safeguards; A person may not be subject to direct coercion (for example, from family member) but may make the decision to request an assisted dying as a result of: • perceived societal pressure ("I feel I must die sooner as I am ill and therefore of no value") • individual circumstances and associated choice ("I want to die sooner so I am not a burden to my wife."	The assessment process allows for the assessing doctors to seek independent psychiatric assessments to help support identification of people who do not want to die but feel pressure to end their lives. If person meets all eligibility criteria set out in law (i.e., has capacity, decision is voluntary and meets all health eligibility criteria) there is a requirement to accept personal decision making as a motivation (i.e., the personal desire to die sooner to avoid being a burden to a loved one).
6.	The safeguarding measures / controls set out in the law may take too long to navigate for an individual with short life expectancy.	The law will set out the minimum timeframe for the assessment process is 14 days under Route 1, but will allow for this minimum timeframe to be shortened if person's death is expected in less than 14 days from the date they make a First Formal Request.
7.	Emotional impact on family members, if the person requesting an assisted death does not inform them / excludes them from decision making process.	Coordinating Doctors will encourage the person to inform family members. Members of MDT will support conversations with the family. Counselling and bereavement support available to family members / friends via the Jersey Assisted Dying Service.
8.	Risk the people will elect to have an assisted death if unable to access palliative care and end of life care.	The 2023 Government plan has committed to between £2 million to £3 million pounds additional annual spend on end of life and domiciliary care provision in Jersey between 2023-2026.

		Report and proposition proposes that assisted dying law would not come into effect unless Assembly is satisfied with the impact of those end of life investments.
9.	Future risk that GoJ disinvests in palliative care and end of life care in future.	Consideration to be given to placing statutory duty on Minister for Health and Social Services to provide palliative care and end of life care as part of proposed Adult Safeguarding Law that is currently in development.
10.	Service and safety complaints and / or legal challenges made (regardless of whether the complaints / challenges are upheld)	Assessment criteria clearly defined in law and assessment guidance. All assisted dying practitioners to undergo mandatory training.
		(Legislation to provide that a professional does not commit an offence if acting in accordance with law and making decisions 'in good faith', having taken reasonable steps even if subsequent evidence to the contrary were to come to light.)
		Clinical guidance, standards and supervision developed by Assurance and Delivery Committee, in consultation with professional bodies and regulators. A referral would be made to a professional regulatory body if fitness to practise concerns around a professional amount to a serious departure from the professional standards. Failure to comply with standards and guidance may also result in investigation by their employer.
		Assisted dying law will create offences of: 'making a false or misleading statement', 'falsifying a document' and 'unauthorised administration of assisted dying substance'. These penalties act as a deterrent for any person who might intentionally act outside of the legislation and would warrant police involvement if professional is suspected to have committed an offence under the law.
11.	Assessing patients' mental capacity for assisted dying requests is complex and can be particularly challenging where the person has psychiatric disorders, such as severe depression, which can impair decision-making capacity.	Specific capacity test for assisted dying to be set out in law. As part of the process the person will be asked to consent to the assessing doctors

accessing the person's medical record. The There is a risk that the assessing doctor this person will be informed that if they do not is not sighted on the full medical record or provide consent, it is likely that the assessing that the patient has an undiagnosed doctor will not be able to make a condition. determination of their eligibility, and the person could not then be assessed as eligible for assisted dying. Assessing doctor must seek a supporting opinion or assessment of specific matters related to a person's eligibility for assisted dying, if the assessing doctor is unable to make a determination on any of the criterion, including decision-making capacity. Depending on the person's medical condition and any comorbid mental illness, a suitable registered health practitioners will carry out a supporting capacity assessment (this may include a psychiatrist, geriatrician, psychologist or specialist social worker). Under 'Route 2 - unbearable suffering' either the Coordinating Doctor or the Independent Assessment Doctor must have expertise in the person's condition or must seek opinion from a professional who does have expertise in the person's condition. 12. Assessment of capacity within process is Specific capacity test for assisted dying to be challenged leading to reputational damage. set out in law. Costs associated with capacity fitness to practise investigation, and (included engagement assessment potential civil claim. capacity specialists provided for in outline budget). Circumstances could include capacity assessments not being carried out when Mandatory training to include detail on they should have been or questions over assessing decision-making capacity. changes in a person's capacity after Requirement for assessing doctors to assessment. arrange supporting assessment or opinion with suitably qualified professional if they are not able to make a determination of decision-making capacity. Even if Waiver of final confirmation of 13. Risk that a person is deemed to have capacity at the time of making a Waiver of consent is in place, if person is shows signs final confirmation of consent but changes of refusal or resistance at the point of their mind later, including at the time of the administration of the assisted dying scheduled assisted death. substance, the Administering Practitioner must not proceed with the assisted death.

14. Risk of medical malpractice during administration of the assisted dying a serious untoward incident or Never person and /or their family, possible injury or protracted / agonised death.

> A never event is a serious incident or error that should not occur if safety procedures are followed.

substance due to poor practice resulting in Event, potentially including distress to the

All assisted dying practitioners to meet professional competency framework standards.

Mandatory training to include training on correct administration of substance.

Assisted Dying Substance Administration Guidance developed by Assurance and Delivery Committee in consultation with professional bodies and regulators.

Agreement to be developed between HCS, JCC and UK professional regulators regarding fitness to practise referrals. Practitioners may be removed from assisted dying practitioner register and either the JCC and / or UK professional registers.

Medical malpractice insurance for Assisted Dying Service to cover all practitioners whilst working for service.

15. The risk of a Never Event due to a person being wrongly assessed as eligible for an assisted death - resulting in an unlawful death, reputational damage due to systemic failings and potential criminal and civil action.

A clear and comprehensive approval process set out in law, which includes:

- a requirement for the person to confirm, as each stage of the process, that they wish to proceed to each step
- two separate assessments undertaken by different assessing doctors requirements placed on assessing doctors to seek specialist opinions / assessments if any doubt as to eligibility (including capacity assessments)
- involvement of MDT members to provide professional challenge to eligibility assessments.

Communications support to be provided if additional the person has any communication needs.

Administering Practitioner to undertake Final Review with person prior administration of substance to confirm they have decision-making capacity and consent to administration of substance.

		T
		Medical malpractice insurance for Assisted Dying Service to cover all practitioners whilst working for service.
16.	Potential for the person's treating healthcare practitioner to be 'distracted' by assisted dying request when treating the patient, leading to substandard or inadequate care or treatment or not giving sufficient consideration to alternative pain relief/ treatment options.	Assisted dying proposals clearly state that the person's ongoing care and treatment continues throughout the assisted dying process and is not affected by their request for an assisted death. This includes, but is not restricted to, any palliative or end of life care and treatment they are receiving.
		Failing to provide adequate care or treatment to the person may amount to a departure from the practitioner's professional standards, which could result in a fitness to practise investigation. Failure to comply with standards and guidance may also result in investigation by their employer.
17.	Jersey is seen a destination for assisted dying tourism.	Anticipated that law will provide that only Jersey residents may eligible for assisted dying. Residential eligibility criteria clearly defined.
18.	Existing HCS staff who are opposed to assisted dying may choose not to continue to work for HCS.	Law will clearly establish that all health and care professionals have right to refuse to direct participation in assisted dying, including any supporting opinions or
	Potential new staff may choose not to accept offers of employment with HCS (even though no staff would be required to work in the assisted dying service).	assessments. Professional must 'opt in' to become assisted dying practitioners.
	May impact HCS's existing recruitment and retention issues.	Information on right to refuse will be provided to all staff / potential staff.
19.	HCS may not be able to recruit sufficient staff to deliver Jersey Assisted Dying Service.	It is proposed that there will be an c.18-month implementation period post adoption of any assisted dying law. This will allow for focused recruitment and training activity
	Potential risk increased as demand for service is not known.	(costs are accounted for in estimated resource and financial implications).
	Projections of anticipated demand have been developed based on numbers of assisted deaths in other jurisdictions, but these projections may not be accurate.	Jersey Assisted Dying Service will work to try to ensure that capacity matches anticipated demand for service.
		If staffing requirements cannot be met on- Island, HCS will look to engage UK-based

	Patients may experience delays to assessments if no assessing doctor is available.	staff to work on a contract basis for Assisted Dying Service.
20.	Implementation of assisted dying legislation may be perceived to conflict with professional registration bodies practice guidance.	There has been extensive dialogue with relevant professional regulatory bodies. This will continue during the legislation drafting phase to ensure legislation and guidance is in line with their standards.
21.	Risk that the emotional and mental health and wellbeing of professionals working for Jersey Assisted Dying Service could be adversely impacted. Secondary impact: Assisted dying practitioners may stop working for the service due to impact on wellbeing.	Service to include provision of professional supervision, debriefing/ peer-support and access to psychological support (costs are accounted for in estimated resource and financial implications). This will be in addition to peer mentoring with experienced practitioners from other jurisdictions.
22.	Harassment or public pressure from individuals or campaigning groups towards professionals who opt-in to become assisted dying practitioners.	List of assisted dying practitioners will not be publicly held. Consideration of protection for professionals and service-users during law drafting process to include safe access zones.
23.	Failure to engage fully with all stakeholder groups (whether as part of the consultation phases, legislation drafting or implementation phase) leading to potential unsafe practice; conflict; harassment of staff; and reputational damage.	Continue engagement with all relevant stakeholders, throughout policy development and implementation phases.

24.	Risk that individual patient's life insurance policies may not pay out in the event of their assisted death. This could: - have financial implications for surviving relatives - give rise to GoJ reputational damage and / or calls for financial recompense	initial consultation with insurance bodies indicates that an assisted death would not impact life insurance policies continued dialogue with Association of British Insurers during the law drafting phase.
		ensure people requesting an assisted death are advised to contact their insurance providers requirement placed on Coordinating Doctor to advise the person to check insurance arrangements as part of assessment process
25.	Risk that GoJ cannot adequately insure assisted dying practitioners under professional indemnity insurance and medical malpractice insurance due to exclusions associated with an Assisted Dying Service. This could result in uninsured loses and individual practitioners at risk of being sued without insurance cover.	Initial discussions with relevant insurance providers indicate that insurance cover for health professionals takes account of the legislation in the jurisdiction in which the health professional is working. Therefore, if assisted dying becomes legal in Jersey, medical indemnity insurance could extend to assisted dying professionals operating within that legislative framework. Medical indemnity insurance is provided for professionals undertaking assisted dying in jurisdictions where assisted dying is already permitted (e.g. Australia, Canada and New Zealand) Continue discussions with relevant professional bodies and Medical Defence Unions, GoJ Insurance Brokerage during law drafting phase.
26.	Risk that GPs and other private practitioners may not be able to secure the necessary insurance to operate as an assisted dying practitioners.	HCS will employ / engage all practitioners working for Assisted Dying Service and would arrange the necessary insurance cover.
27.	In the event of a successful malpractice claim, the HCS would be required fund any excess, which may be a significant amount per claim. Excesses associated with claims have recently increased.	This is a live risk which would apply to any HCS malpractice claims.

28.	Risk that cost of premiums and excesses have negative impact on HCS overall budget, requiring costs savings in other areas of activity.	Requirement for the Assembly to provide the necessary funds to the Jersey Assisted Dying Service (including associated insurance costs) to ensure no requirement for HCS cost saving arises from the provision of the Service.
29.	Report and proposition includes breakdown of anticipated service costs. Risk that these costs are incorrect or rise.	Updated cost estimates will be presented alongside the draft law prior to the final States Assembly debate on assisted dying – it is anticipated this will take place at the end of 2025.
30.	Suicide (Current risk) someone with a terminal illness or unbearable suffering attempts suicide due to: - degree of suffering - inability to access palliative / end of life care Associated emotional and potential financial impact on family and friends.	Introduction of assisted dying law provides a legal framework for a person to who meets the eligibility criteria, which includes suffering that they determine to be unbearable, to end their life. That legal framework provides support for the person and their loved ones and works to reduce loneliness and fear. Report and proposition proposes that
		assisted dying law would not come into effect unless Assembly is satisfied with impact of recent investments in palliative and end of life care (which will support wider access).
31.	Suicide (Future risk) someone who wishes to use the assisted dying to end their life does not meet the criteria under the Law decides to attempt suicide leading to possible further harm to themselves or completion of suicide.	Proposals set out clear pathways for accessing support and additional care or treatment for those assessed as not eligible for assisted dying.
	Associated emotional and potential financial impact on family and friends.	

580. A full risk assessment will be undertaken as part of the legislation development process and will be presented to the States Assembly alongside the draft law. The full risk assessment process cannot meaningfully commence until the Assembly has determined the key provisions of the law as set out in this report and proposition.

Next steps

581. In the event the Assembly adopts this proposition, work will commence of the development of a draft assisted dying law.

- 582. Given the detail and complexity of these proposals, it is anticipated that the law drafting process will take 12-18 months. It is anticipated that debate on the draft law will take place before the end of 2025, but this may be subject to change.
- 583. Should the Assembly adopt the draft law, it is proposed that an implementation period of a minimum of 18-months is set in place. Prior to the law coming into force, the following actions will need to be undertaken:
 - a. HCS will recruit / contract the assisted dying practitioners and Care Navigators who will deliver the service
 - b. Development and delivery of the assisted dying training package for assisted dying practitioners
 - c. Development of Assisted Dying Person Record
 - d. the Minister to publish the necessary guidance and all the necessary forms by Order
 - e. establish Assurance and Delivery Committee and Jersey Assisted Dying Service and Committee to develop and publish all relevant guidance and clinical practice protocols
 - f. Assurance and Delivery Committee to establish the Assisted Dying Review Panel and develop its working protocols
 - g. the Judicial Greffe will to have make the necessary arrangements for the assisted dying tribunal
 - h. Rules of Court will need to be developed in relation to appeals
 - i. a dedicated assisted death certification process to be implemented
 - j. bespoke webpage and public-facing information developed and made available in accessible formats.

List of appendices

Appendix 1: Policy changes / clarifications

Appendix 2: List of safeguards and case studies

Appendix 3: Forms and guidance

Appendix 4: Outline of mandatory training

Appendix 5: Timeline of activity

Appendix 1: Policy changes / clarifications

Purpose of appendix

The assisted dying proposals, as set out in the report and proposition, have been informed by an extensive consultation and development process (summarised in the table below) which has resulted in numerous changes / clarifications to the proposals initially brought forward by Jersey Assisted Dying Citizens' Jury⁵³.

September 2021	Final report & recommendations from Jersey Assisted	
	Dying Citizens' Jury ⁵⁴	
November 2021	P95/2021 Assisted Dying – States Assembly 'in	
	principle' debate ⁵⁵	
March - May 2022	Phase 1 consultation and publication of public	
	engagement summary report ⁵⁶	
May - October 2022	Development of draft proposals (input from Phase 1	
	consultation, HCS Professional Leads working group	
	and expertise from other jurisdictions) ⁵⁷	
October 2022 - January	Phase 2 public consultation on draft proposals ⁵⁸	
2023		
April 2023	Public consultation feedback published ⁵⁹	
November 2023	Publication of Ethical Review ⁶⁰	

This appendix summarises the key changes / clarifications to the proposals recommended by Jersey Assisted Dying Citizens' Jury and adopted, in principle by the States Assembly (P95/2021). It also provides a high-level rationale for those changes / clarifications.

The appendix does not set out the policy rationale for all the elements of the report and proposition which have not be subjected to change, details of which can be found in the Assisted Dying Phase 2 Consultation Report⁶¹.

⁵³ Citizens' Jury on assisted dying in Jersey (gov.je)

⁵⁴ Final Report from Jersey Assisted Dying Citizens' Jury (gov.je)

⁵⁵ Full R+P: <u>P.95-2021.pdf (gov.je)</u>, as amended: <u>P.95-2021 Amd.pdf (gov.je)</u>

⁵⁶ Public engagement summary report on assisted dying in Jersey (gov.je)

⁵⁷ Assisted dying in Jersey (gov.je)

⁵⁸ Consultation page: <u>Assisted dying in Jersey consultation (gov.je)</u> and report on proposals: <u>Assisted Dying Consultation Report.pdf (gov.je)</u>

⁵⁹ Consultation feedback report: <u>Assisted Dying in Jersey Phase 2 Consultation Feedback Report (gov.je)</u>

⁶⁰ Assisted Dying in Jersey Ethical Review Report (gov.je)

⁶¹ Assisted Dying Consultation Report.pdf (gov.je)

Key changes / clarifications

1. Underpinning Principles

The Phase 2 consultation set out six underpinning principles, each of which had been shaped by feedback arising from:

- Citizens' Jury recommendations
- Phase 1 engagement
- Discussion with Professional Leads working group
- Learnings from other jurisdictions

The feedback to the Phase 2 consultation included comments which were focused on two of the six underpinning principles – 'palliative care / end of life care services' and 'assisted dying is not suicide'.

a. Palliative / end of life care services

Phase 2 consultation set out that '... legislation permitting assisted dying should not be brought into force until the Assembly is satisfied that all Islanders can access good palliative and end-of-life services.'

Some respondents supported this as a necessary 'safeguard' prior to the introduction of assisted dying, helping to support provision of good quality palliative / end of life care options and ensuing that funding for palliative / end of life care is not 'diverted' to the assisted dying service.

Other respondents challenged the wording of the draft proposals citing a lack of clarity and measurable outcomes.

In response to this challenge, the report and proposition has been updated to improve clarity and to specifically require that prior to any legislation coming into force the Assembly must be:

"satisfied that decision taken in the 2023 Government Plan to provide for additional investment in end of life and palliative care is supporting improvements in quality and availability of those services.

This will require information and evidence that improvements are in train, to be presented to the Assembly as part of any future debate on an appointed day act to bring the anticipated assisted dying law into force."

It is anticipated that the evidence brought forward will relate directly to the key metrics for success outlined in the *Palliative and End of Life Care Strategy for Adults in Jersey* which was published in November 2023.

b. Assisted dying is not suicide

The Phase 2 consultation stated that 'assisted dying is not suicide'. Some respondents were supportive of this statement (for example, the Attorney General of South

Australia), others opposed to the statement (for example, submissions from campaigning organisations, including the Christian Institute).

Whilst it is acknowledged that assisted dying and suicide are both acts which are intended to end one's own life, it is the case that suicide is lonely act, carried out outside of a legal framework which often leaves behind a legacy of stigma and irresolvable grief for loved ones. Assisted dying is carried out within a clear legal framework, and the associated process will offer both support to the person requesting the assisted death and their loved ones.

For this reason, the distinction between assisted dying and suicide is retained as an important principle.

Underpinning Principles: Summary of key changes / clarifications

- The report and proposition sets out that there should be a clear link between
 the introduction of the assisted dying law and evidence that additional
 investment has supported improvements in the quality and availability of
 palliative / end of life care.
- The principle that 'assisted dying is not suicide' is retained.

2. Regulation making power

The Phase 2 consultation proposed that the law should provide a broad Regulation-making power allowing the Assembly to amend the eligibility criteria in the event the Assembly deems it appropriate to do so in future.

Some respondents expressed concern over the potential for a 'slippery slope' of expanding eligibility criteria, particularly with regard to potential expansion to allow assisted dying for those aged under 18.⁶²

Regulation make power: Summary of key changes / clarifications

The report and proposition has been amended to remove the power to amend the eligibility criteria by Regulation. Any future changes to the eligibility criteria will require an amendment to the primary law, which would require Privy Council consideration and Royal Assent of any amendments adopted by the Assembly.

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⁶² Appendix A - assisted dying consultation phase 2 organisation responses.pdf (gov.je)

3. Eligibility criteria

The Table below summaries changes / clarifications to the eligibility criteria which were made during the policy development process. Amendments to the wording of the proposed criteria are highlighted in grey.

Proposed criteria are highligh		Summary of change	Rationale for change /
		/ clarification	clarification
	P95/2021		
a.	aged 18 or over		
b.	Jersey resident		
c.	voluntary, clear, settled and informed wish to end their own life		
d.	capacity to make the decision to end to their own life		
e.	been diagnosed with a terminal illness, which is expected to result in unbearable suffering that cannot be alleviated and is reasonably expected to die within six months, OR		
f.	has an incurable physical condition, resulting in unbearable suffering that cannot be alleviated.		
H u	SEE NOTE BELOW: Route 2 – unbearable uffering		

Phase 2 consultation

- a. aged 18 or over
- b. Jersey resident (ordinarily resident for at least 12 months), and
- voluntary, clear, settled and informed wish to end their own life,
- d. capacity to make the decision to end to their own life
- e. (i)has been diagnosed with terminal a physical medical condition, which is expected to result in unbearable suffering that cannot be alleviated in a manner the person deems tolerable and where the person is reasonably expected to die within six months
- e. (ii)has been diagnosed with a

- 1. defines
 'resident' as
 '12-months
 ordinarily
 resident' in
 Jersey at the
 time of the first
 assessment
- 2. inclusion of 12month life expectancy for terminal neurodegenerat ive conditions
- 3. 'giving rise to'
 unbearable
 suffering
 'cannot be
 alleviated in a
 manner the
 person deems
 tolerable'

- 1. 12-months residency aims to strike balance between not excluding those who have recently moved to the island and preventing 'assisted dying tourism'
- inclusion of 12-month life expectancy for terminal neurodegenerative conditions – reflects approach in a number of Australian states to the nature neurodegenerative diseases for example motor neurone disease, a person is likely to see a significant deterioration quality of life and associated potential for unbearable suffering significantly before they reach the point of having six month's life expectancy.

SEE NOTE BELOW: Route 1 life expectancy timeframe.

3. for 'Route 2' update in language to 'giving rise to' unbearable suffering from 'resulting in' in order to clarify that suffering must be current, rather than the person being expected to experience suffering at a future date. And the addition of cannot be

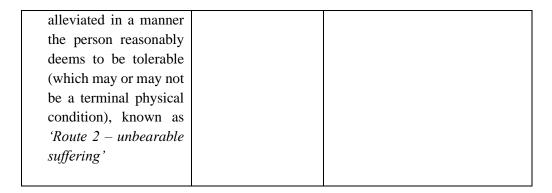
physical medical condition that is neurodegenerative, which is expected to result in unbearable suffering that cannot be alleviated in a manner the person deems tolerable and where the person is reasonably expected to die within twelve months; [Route 1 – terminal illness]		alleviated 'in a manner the person deems tolerable' to acknowledge a person's right to refuse treatment – for example a patient may decline chemotherapy because of the associated adverse side-effects, even if it could potentially result in slightly longer life expectancy.			
physical medical condition that is giving rise to unbearable suffering that cannot be alleviated in a manner the person deems tolerable [Route 2 – unbearable suffering].					
Ethical Review	Ethical Review				
-	_	No recommended updates, but 'Route 2' proposal not			
		supported [see 'Route 2 –			
		Unbearable Suffering' below]			
Report and proposition (incorporating key elements of Phase 2 consultation feedback)					
a. the person must be aged 18 or over at the point at which they make a first formal request for an assisted death;	Precision of definitions: 1. current suffering for those with a terminal	Following consultation feedback definition of 'Route 1' updated to improve clarity: 1. to clarify that those eligible under Route 1 may either be experiencing current			
b. the person must be ordinarily resident in Jersey [for a period of	condition	suffering OR expected to experience suffering in the future			

- at least 12 months before they make a first formal request for an assisted death];
- the person must have a voluntary, clear, settled and informed wish to end their own life; and
- d. the person must have capacity to make the decision to end their own life;
- the person must have been diagnosed with a terminal physical medical condition which is giving rise to, or is expected to give unbearable rise to, suffering that cannot be alleviated in a manner the person reasonably deems to be tolerable that terminal and condition must be reasonably expected to cause the person's death within 6 months, or 12 months in the case of neurodegenerative conditions, known as 'Route 1 – terminal illness';

OR

f. the person must have an incurable physical condition that is giving rise to unbearable suffering that cannot be

- causal link between eligible health condition and life expectancy
- 2. to clarify that the person's life expectancy must be directly related to the terminal condition that made them eligible for assisted dying and not any other 'and where the reason: is reasonably person expected to die within 6 months' has been updated to 'and that terminal condition must be reasonably expected to cause the person's death within 6 months'



NOTE: Route 2 – unbearable suffering

In adopting P95/2021, the Assembly agreed in principle that assisted dying should be permitted for people with a terminal illness (referred to as 'Route 1 – terminal illness') and people with an incurable physical condition, resulting in unbearable suffering (referred to as 'Route 2 – unbearable suffering').

As the provision of 'Route 1' and 'Route 2' has been agreed in principle by the Assembly, the Phase 2 consultation survey did not include a specific question on whether both Routes should be permitted, and as a result, the consultation feedback did not report a percentage of those who were supportive of 'Route 1 – terminal illness', but not supportive of 'Route 2 – unbearable suffering.' However, it should be noted that a significant number of respondents did express specific reservations about 'Route 2 – unbearable suffering'. Feedback included:

- ethical concerns about permitting assisted dying for people who are not at the end of life
- a greater deviation from current medical practice i.e., assisting people to die who are not already dying is not as readily comparable with existing medical practice and decision-making processes for health and care professionals
- concerns over fluctuation of suffering over the longer term for a person with no terminal diagnosis i.e. person may, in time, 'come to terms' with their condition and suffering
- risk of 'slippery slope' in terms of further changes to eligibility criteria in future, if 'Route 2' is introduced (for example expanding to those with mental illness) vs. 'tight' definition of those with a terminal illness (Route 1)
- concerns over data that indicates greater uptake of assisted dying in jurisdictions that allow assisted dying for those with unbearable suffering vs. those that allow for terminal illness only
- concern around the impact on wider society if law allows assisted dying for those who are not 'already dying'. With a potential shift in societal norms including the value placed on life in a general sense, and more specifically the potential for judgements as to the value of life for people who experience suffering, older people and people with disabilities.

Given the lack of consensus amongst consultation respondents, the Ethical Review Panel was asked to give specific consideration to the inclusion of both Route 1 and Route 2. The Review authors commented:

"we have serious reservations about allowing AD in such circumstances [i.e., where a person is not terminally ill] and on balance we believe that the proposals regarding Route 2 are not ethically appropriate... Route 2 raises significant concerns because it: makes (and reinforces) an "ableist" judgment about the negative value of the lives of people with disabilities; relies on perceptions of the tolerability of suffering, which may change over time and be influenced by social and psychological factors; rests on a concept – "suffering" – which is too vague, multifaceted and subjective to be a reliable eligibility criterion; and, given its inherent subjectivity, may lead to the expansion of AD in terms of numbers and scope."

The proposition, in accordance with P95/2021, includes both 'Route 1 – terminal illness' and 'Route 2 – unbearable suffering' but, given the feedback received, it is constructed so that the Assembly has the option to adopt both Routes or 'Route 1 – terminal illness' only (or, in theory, Route 2 only).

NOTE: Route 1 - life expectancy timeframe

In adopting P95/2021, the Assembly agreed, in principle, that assisted dying should be permitted for those with a terminal illness and a life expectancy of 6 months. Reflecting feedbacked received (and learning from other jurisdictions), this provision was extended in the Phase 2 consultation proposals to also allow for a 12-month life expectancy timeframe for people with a neurodegenerative terminal condition.

The feedback to this amended proposal was mixed, with 48% of Phase 2 Consultation respondents supportive of the 12-month timeframe for neurodegenerative conditions, 45% not supportive, and 7% responding 'don't know'. Additional consultation feedback highlighted the acknowledged inherent difficulties in accurately predicting life expectancy, with some respondents suggesting the solution was to remove any associated timeframe with a terminal diagnosis (i.e., a person simply requires a terminal prognosis to be eligible for assisted dying, regardless of their life expectancy). Other respondents were of the view that having a timeframe attached to a terminal diagnosis was better than *no* timeframe, even though it is recognized that timeframes can be inaccurate.

The Ethical Review also commented on the matter noting that:

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⁶³ Ableist judgment refers to prejudice, discrimination and value judgments aimed towards people with disabilities

- there are legal precedents in other jurisdictions for including a specific lifeexpectancy prognosis
- providing clear timeframes offers a more objective measure for determining who would (not) have access to AD. Doing so reserves AD for the "already dying"
- providing clear timeframes helps to delineate permissible practice and prevent the expansion of AD.

The Review also considered the 6-month timeframe for non-neurodegenerative conditions under 'Route 1 - terminal illness', noting that studies indicate that overestimation of life-expectancy is more likely than under-estimation (which could support a timeframe of <u>longer than</u> 6 months) but also that survival estimates become more reliable the closer the patient is to death (which could support a timeframe of less than 6 months).

Therefore, the proposed 6-month timeframe may strike the appropriate balance between these two tensions. It is also the case that the '6-month' timeframe features in legislation in several other jurisdictions including Oregon and other US States, New Zealand, Austria and Australia (in which a number of states also allow for the 12-month timeframe for neurodegenerative conditions), plus proposals for legislation in the Isle of Man.

The Ethical Review authors concluded, on balance, that the Route 1 proposals were 'ethically appropriate' and aim to 'strike an appropriate balance between empowering and protecting people', as stipulating particular timeframes can act as a safeguard.

4. Jersey Assisted Dying Service

a. Jersey Assisted Dying service to be delivered by HCS

In adopting P95/2021, the Assembly agreed in principle that the "Government of Jersey should make arrangements for the provision of an assisted dying service".

The proposed structure of the Jersey Assisted Dying Service was described in the Phase 2 consultation, having been informed by feedback received, and learning from other jurisdictions.

The Professional Leads working group gave detailed consideration to the arrangements for establishing and delivering an assisted dying service in Jersey, including consideration of the following options:

Commissioning for an off-island external provision: would be contrary to the Assembly decision to make provision for an 'assisted dying service in Jersey'; would have a significant impact on the patient's experience; would make it significantly more difficult to apply safeguards and ensure service quality.

Commissioning off-island external providers to operate in Jersey: jurisdictions that permit assisted dying generally provide the service within their standard national health service arrangements (i.e. they do not use external providers), with the exception of Switzerland and Germany where the service is provided by not-for-profit organisations (NPOs) including Dignitas. These NPOs operate in jurisdictions where there is no explicit legislative and regulatory frameworks for assisted dying provision, and therefore are not experienced in operating within the context proposed for Jersey.

Commissioning on-island external providers to operate in Jersey: there are currently no providers on Island with expertise or experience to deliver an assisted dying service. Whilst it would be possible for an external organisation to establish an assisted dying service, there would be concerns about the ability of Government to provide sufficient oversight of such a service.

The proposition is, therefore, predicated on the basis of Health and Community Services establishing and delivering the service but proposed that:

"the law should not preclude the Minister from making arrangements for a different entity [i.e., an entity other than HCS] to provide the Jersey Assisted Dying Service if, as some point in the future, the Minister were to be satisfied that another entity were better placed to manage and deliver the service, and that the entity would do so in accordance with the law."

b. Consideration of medical model vs. non-medical model of assisted dying

The proposals provide that the Jersey Assisted Dying Service will be a 'medical model' (i.e., doctors are central to delivery of the service, determining eligibility etc.) as opposed to a 'non-medical model' (i.e., decisions as to eligibility and the delivery of an assisted death are carried out by people other than doctors, for example trained laypeople or lawyers).

Consultation feedback on the matter was varied and was not dependent on views towards assisted dying – there was feedback from those supportive and those opposed to assisted dying, both *in favour* and *opposed* to a medical model.

Many viewed assisted dying as natural extension of the healthcare service (we provide for end-of-life care, and assisted dying is an end-of-life choice) and, as such, stated that assisted dying should be integrated into care provision.

Others saw assisted dying as being about personal choice and entirely unrelated to health care / treatment. This 'non-medical' view of assisted dying bears similarities to the model provided in Switzerland. Some proponents of the 'non-medical' view (predominately supporters of assisted dying) state that assisted dying is about personal choice— not about medical intervention or expertise. Others (predominately opponents of assisted dying) advocate the 'non-medical' approach as it upholds the right for medical professionals to conscientiously object and does not disrupt or interfere in the relationship between medical professionals and patients.

The Ethical Review gave specific consideration to proposed adoption of 'medical model' of assisted dying.

The Review considered practical arguments for and against the involvement of doctors which centred around their willingness to provide assisted dying. The Review also noted principled arguments both in favour and against the involvement of doctors in assisted dying, centring on whether the core purpose of doctors is to 'cure and heal' or to 'prevent suffering'. The Review authors remarked that the principled arguments for and against a medical model appear to be inconclusive but noted that, on balance, total demedicalisation does not appear to be ethically defensible.

On and off-Island health and care professionals engaged in the consultation process giving views on the 'medical model' and also their theoretical willingness to participate, both by responding to the survey and providing written feedback, as well as attending in-person consultation events, including engagement sessions dedicated to health and care professionals. In addition, the British Medical Association (BMA) provided feedback on behalf of their members, which includes Jersey-based doctors.

As well as sharing views on the proposals, a number of professionals discussed their willingness to participate in assisted dying, should legislation be approved. This data was not captured on a quantitative basis, but feedback included professionals stating they 'definitely would' and 'definitely would not' participate, as well as those who stated they were undecided or that their decision would be dependent on the final proposals.

The Ethical Review authors recommend that once the assisted dying proposals have been confirmed [i.e. *after* the Assembly debate on this proposition], further work is undertaken to survey local health and care professionals regarding their willingness to participate in assisted dying. This would support a better understanding of the potential implementation challenges and the likely requirement for 'off island' practitioners prior to the approval of a draft law.

Professionals cannot be consulted in any meaningful way on participation in the service until the Assembly have determined the associated legal provisions.

c. Oversight by HCS Delivery and Assurance board / committee

The Phase 2 consultation proposals set out that a dedicated HCS Delivery and Assurance board / committee would be established to oversee the delivery of the Jersey Assisted Dying Service and to provide the necessary clinical and governance oversight [in addition to that which will be provided by the Jersey Care Commission].

72.2% of survey respondents agreed that an oversight board was needed. Further to this, 66.5% of survey respondents agreed that the Committee should commission a post-death administrative review after each death.

In response to the feedback received, the report and proposition further clarifies the role and remit of the proposed Assisted Dying Assurance and Delivery Committee and the Assisted Dying Review Panel who will carry out post-death reviews [see Section 5: Jersey Assisted Dying Service and Section 11: Regulation and Oversight]

d. Publication of annual report on assisted dying

The Phase 2 consultation proposed that the Jersey Care Commission would publish an annual report on assisted dying, ensuring complete public transparency as to the number of requests for assisted dying, and the number of assisted deaths.

Consultation feedback challenged this approach, stating that regulatory oversight reports (i.e., the service inspection reports published by the Jersey Care Commission) should be separate from reports on the provision of assisted dying in Jersey. As such, the report and proposition sets out that the Assisted Dying Assurance and Delivery Committee must publish an annual report on the activity of the Jersey Assisted Dying Service and that the Committee must consult the Medical Officer for Health to confirm the data to be presented in that annual report and to agree the methodology for compiling the data.

Jersey Assisted Dying Service: Summary of key changes / clarifications

- Following 'in principle' decision that GoJ should make arrangements for
 provision of an assisted dying service, proposals put forward that the Jersey
 Assisted Dying Service should be delivered by HCS but that the law would
 allow for a different entity to provide the Jersey Assisted Dying Service, if
 deemed appropriate by the Minister at some point in the future.
- Assisted Dying Assurance and Delivery Committee must publish annual report, having sought advice from the Medical Officer for Health.

5. Health and care professionals

a. Conscientious objection – right to refuse direct participation

In adopting P95/2021, the Assembly agreed in principle that an assisted dying law should provide for a conscientious objection clause so that any nurse, medical practitioner or other professional, who conscientiously objects to assisted dying, is not under a legal duty to participate in assisted dying.

The Phase 2 consultation proposed that the conscientious objection clause should be restricted to 'direct participation' in line with comparable provisions in the termination of pregnancy law, and asked whether the conscientious objection clause should extend beyond direct involvement in the service to also include:

- professionals who provide supporting opinions or assessments but who are not directly involved in the assisted dying process, and / or
- premises operators (for example, care home providers).

Respondents indicated strong support for the proposed extension (78.6% of respondents supported the right for professionals to refuse to provide supporting opinions and 58.8%

supported the right for premises operators to refuse to allow a person to have an assisted death on their premises).

In addition, other stakeholders, including the British Medical Association (BMA) stated that the right to refuse to participate should be extended to include direct participation on <u>any grounds</u> (for example, emotional impact on the professional or the professional's other patients) as opposed to be limited to the grounds of conscience or belief.

In response to this feedback these proposals have been amended to:

- extend the right to refuse on any grounds (not just conscientious objection)
- extend the definition of direct participation to include both professionals providing supporting opinions or assessments and premises operators.

b. Registration of assisted dying practitioners

The purpose of registration of assisted dying practitioners is to maintain a record of appropriately qualified professionals who may work for the Jersey Assisted Dying Service.

The Phase 2 consultation asked whether the register of assisted dying practitioners should be publicly available. 55.3% of respondents to the consultation survey felt the register should be publicly held, whilst 20% responded 'don't know'. The associated comments explored the tensions between a desire for transparency vs. respecting the privacy of practitioners in a small island jurisdiction, with some respondents suggesting access to the register should be restricted.

There has been detailed discussion with the UK Professional Regulators about this matter, who acknowledge the complexity of a public register in a small jurisdiction. Whilst it is acknowledged that transparency is important, it has been determined that, on balance, the register should not be held publicly. This is to protect the privacy of practitioners, and specifically to minimise the potential of them being subject to abuse by those who hold strong views on the subject. The report and proposition set out that whilst registration details will not be published, information about a registrant can be shared with relevant organisations and office / post holders who may need access to this information for the purpose of oversight, regulation and safeguarding in relation to assisted dying processes.

c. Discussion of assisted dying with patients

The Phase 2 consultation report posed two questions on the matter of professionals discussing assisted dying with patients. These are summarised below:

Do you agree the law should not prohibit professionals from raising the subject of assisted dying?

- Yes, I agree 48%
- No, I do not agree 44.2%

Do you agree the law should not place an explicit requirement on professionals to tell people about the assisted dying service?

- Yes, I agree 70.2%
- No, I do not agree 21.2%

The combined responses indicate support for the law to remain 'silent' on professionals discussing assisted dying with patients (i.e., professionals are neither compelled to raise the subject or prohibited from doing so).

This matter was considered by the Ethical Review. In summary the Review authors agreed that for Route 1 the law should remain silent, but noted that are specific concerns associated with Route 2 if a professional proactively raises the subject of assisted dying: "When a person is not approaching their natural death, offering AD would convey to the person (who may potentially have years or decades of life remaining) the message that death is a reasonable option for them. Many people with disabilities would consider this to be offensive, as it would convey a message that death is a reasonable option for persons faced with a disability or chronic illness. There is a heightened concern about how this may impact on resilience."

The report and proposition therefore states that the law will remain 'silent' on the discussion of assisted dying with patients, but that the Minister will bring forward 'Appropriate Conversations Guidance' which will clarify the circumstances where raising the issue of assisted dying may be appropriate, setting out that it is unlikely to be appropriate to proactively raise with a patient who does not have a terminal illness (i.e., who may be eligible under 'Route 2 – unbearable suffering', as opposed to 'Route 1 – terminal illness').

This position is supported by key professional regulatory bodies - the GMC (General Medical Council) and NMC (Nursing and Midwifery Council).

Health and care professionals: Summary of key changes / clarifications:

- Law will include right to refuse to directly participate on any ground and will extend that right to professionals providing supporting opinion / assessments and premises operators.
- Register of assisted dying practitioners not to be publicly held.
- Law to be silent on discussion of assisted dying with patients. Minister to publish *Appropriate Conversations Guidance* and provide training for health and care professionals.

6. Assisted dying process

a. Minimum timeframes

In adopting P95/2021, the Assembly agreed in principle that an assisted death should be subject to a mandatory period of reflection (which effectively requires a mandatory minimum timeframe). The Phase 2 consultation proposed the following minimum timeframes which were informed feedback received and learning from other jurisdictions. The minimum timeframes cover the time period for a person's first formal request for an assisted death to the administration of the assisted dying substance:

- a minimum of 14-days for those eligible under 'Route 1 terminal illness'
- a minimum of 90-days for those eligible under 'Route 2 unbearable suffering'

The Phase 2 consultation sought views on the proposed minimum timeframes. Those views were very mixed with no clear majority support for either the 14-day time frame for those eligible under Route 1 or the 90 days for those eligible under Route 2. Whilst some respondents were supportive of the timeframes as proposed, some felt they should be longer, and some felt they should be shorter. This mixed response was reflected both in individual responses and responses from stakeholder organisations.

The Ethical Review considered the matter of minimum timeframes, noting arguments for and against their inclusion which can be summarised as the trade-off for a safeguard intended to allow reflection and assessment vs. prolonging a person's suffering when their decision is clear. The Review authors concluding that imposing specific, and distinct, minimum timeframes is appropriate and that proposed timeframes align with other regimes and appear to strike an appropriate balance.

On this basis, the report and proposition maintain the timeframes originally proposed in the consultation report (i.e. 14 days for Route 1 and 90 days for Route 2) except that, in response to the concerns around prolonging suffering, they provide that there will be no minimum timeframe where the person is eligible for an assisted death and has a life expectancy of less than 14 days from the date of their first formal request.

b. Second opinion assessment

Where a person is not assessed as eligible for an assisted death, they may request a second opinion. The Phase 2 consultation survey asked whether a person should only be entitled to one second opinion (either during the first assessment or during the second independent assessment) in order to prevent inappropriate repeat requests.

There was no consensus response (38% in agreement, 35% disagree and over 25% responding 'don't know') for the survey, although feedback from the GMC was clear that if legislation were to limit a person's right to only being able to have a single second opinion, it may be unnecessarily inflexible and it might not be in line with their 'Good medical practice' guidance.

The report and proposition has, therefore, been updated to clarify that the right to a second opinion will be a matter of practice and guidance and that a person may request a second opinion at both the first and second assessment, because there may be valid reasons for requesting a second opinion at each stage of the process i.e., the number of second opinions will be not be restricted in law.

c. Multidisciplinary team to support assessment process

During the Phase 2 consultation process, multiple stakeholders expressed the view that the assisted dying assessment process could be more robust if it included the involvement of other professionals, in addition to the assessing doctors. This included feedback during the in-person public sessions and the dedicated health care professionals' sessions.

The report and proposition has, therefore, been updated to set out that the Jersey Assisted Dying Service will include a multidisciplinary team ("MDT") who will provide check and challenge for the assessing doctors and a multidisciplinary perspective to discussions of eligibility.

d. Approval routes

In adopting P95/2021 the Assembly agreed, in principle, that any assisted death should be subject to an approval process which, subject to further consultation, may involve a decision made by a court or specialist tribunal.

Based on feedback from the Phase 1 engagement process, the Phase 2 consultation proposed different approval routes for:

- 'Route 1 terminal illness' approval by Coordinating Doctor, following two assessments
- 'Route 2 unbearable suffering' approval by Coordinating Doctor, following two assessments, with that approval being confirmed by a Tribunal.

The Phase 2 consultation survey requested feedback on the proposed approval routes. The feedback demonstrated a lack of a clear preference, with mixed views on the proposals:

- 24% of respondents agreed with the proposed approval routes
- 21% were of the view that all assisted deaths should be approved by Tribunal
- 26% were of the view that all assisted deaths should be approved by the Coordinating Doctor, with no Tribunal involvement
- 29% responded 'don't know' or 'other'

In support of a Tribunal for 'Route 2 – unbearable suffering' feedback focussed on the additional integrity and accountability that a Tribunal would provide to the process, benefitting both the person and professionals involved. Against this, feedback noted that involvement of a Tribunal was out of step with most other jurisdictions and that the process could place an excessive burden on the person and increase the time taken to

approve an assisted death as well as result in significant additional costs to set up and run a Tribunal.

The rationale for separate approval routes, and the additional step of Tribunal approval under 'Route 2 – unbearable suffering', centres around the additional complexity of assessing eligibility of a person under 'Route 2', which rests solely on subjective criteria of the 'unbearableness' of the person's suffering and does not include determination of eligibility against more 'measurable' criteria such as expected life expectancy.

The Ethical Review raised similar points in favour and against the inclusion of a Tribunal as provided in the consultation feedback. In addition, the Review noted that the inclusion of a Tribunal for Route 2 – unbearable suffering, may enhance the objectivity in the decision-making and reduce the potential for error, abuse or legal ramifications and that a broadly composed Tribunal, which includes legal representation, may also somewhat address concerns about medicalisation. They noted that a similar provision of prospective (as opposed to *retrospective*) review and approval by a relevant authority also exists in Spanish law and can act as additional safeguard, with 'three filters' i.e. the Coordinating Doctor, Independent Assessment Doctor and Tribunal that must all be in agreement that the person meets the eligibility criteria.

The Review authors concluded that on balance, it is reasonable to make a fundamental distinction between assisted dying in an end-of-life context, and assisted dying outside the end-of-life context- and that there is no injustice, inequality or inequity in treating these different cases differently via different approval routes.

e. Expiry of approval

P95/2021 was silent on the matter of expiry of approval (i.e., it did not propose whether or not an approval for an assisted death should have an expiry date). Based on feedback received during the Phase 1 consultation, the Phase 2 consultation proposals set out that there should not be an expiry date for an assisted dying approval. This is to ensure that pressure is not placed on the person to end their life through an assisted death when they are not yet ready to do so, purely because their approval is close to expiry.

Evidence from other jurisdictions suggests that, in some cases, the knowledge that a person has the option to end their suffering (because their assisted death has been approved) brings such comfort that they choose not to proceed to an assisted death. For example, in Western Australia in 2022 around 28% of people who were approved for an assisted death, did not go on to have an assisted death.

The majority of survey respondents during the consultation were supportive of this (53%), with 27% disagreeing.

Assisted dying process: Summary of key changes / clarifications

- Minimum timeframes are retained at 14 days for 'Route 1' and 90 days for 'Route 2', except for where a person who is eligible under Route 1 has a life expectancy of less than 14 days, in which case there will be no minimum timeframe.
- The right to a second opinion will be a matter of practice and guidance, the law will not restrict a person to one second opinion only.
- A multidisciplinary team will be established to support the assessing doctors in their determination of eligibility.
- There will be 2 separate approval routes set out in law.
- There will be no expiry of approval.

7. Appeals

Whilst P95/2021 did not provide for an appeal process, the Phase 2 consultation proposals did propose that provision is made in Jersey law to provide for a right of appeal to the Court, which in turn will help support public confidence in the assisted dying process.

It should be noted that most jurisdictions do not provide for an appeal process within their assisted dying legislation, although most Australian states do allow for appeal to an Administrative Review Tribunal (as opposed to appeal to a Court).

Feedback from the Phase 2 consultation indicated broad support for the inclusion of an appeals process, as set out in the proposals, with 61% of survey respondents agreeing that the law should provide for appeals to the Royal Court. 63.3% also agreed that the right to appeal should be restricted to the person (or their agent) or a third party with special interest in care and treatment of the person, in order to avoid disruptive appeals by unconnected third parties (such as representatives of lobby groups).

There was less clear support for the proposed 48-hour minimum timeframe between approval and the assisted death to allow for appeals to be lodged. Some respondents who were supportive of assisted dying felt that 48 hours simply prolonged the person's suffering, whilst some respondents who are opposed to assisted dying felt that 48 hours was not sufficient time for a family member or other person with special interest in the care and treatment of the person to make an application for appeal.

Further consultation with the Judicial Greffier updated this to 'two working days', instead of 48 hours, to allow for situations where, for example, approval is granted

immediately prior to a bank holiday, in order to have sufficient opportunity to make an application for appeal.

The Ethical Review considered the proposed appeals process and set out arguments both in favour and against appeals. The Review authors noted that on balance, it was appropriate to include an appeals process as:

- there is a precedent for this (Australian administrative tribunal appeals)
- it may help build public confidence (majority of consultation respondents were supportive)
- it may prevent or limit under-inclusion and over-inclusion (i.e. help to ensure
 that people who should be eligible are not excluded from accessing assisted
 dying and conversely it can help to ensure that people who should not be
 eligible are not given access)
- it places assisted dying within the legal domain, which may temper some of the concerns about a 'medical model' (i.e., the involvement of non-medical professionals in the decision-making process)
- it may, over time, contribute to consistency in decision-making since appeals decisions may guide health and care professionals in future cases about the boundaries of eligibility as determined by the Court.

The Review also noted that with appeals, the assisted dying process would be prolonged, but arguably not excessively so, at least relative to the safeguards an appeals process brings. As such, these proposals confirm the appeals process proposed in the Phase 2 consultation report.

Appeals: Summary of key changes / clarifications

- The law will set out an appeals process to the Royal Court. An appeal can only be made by the person (or their agent) or a third party with special interest in care and treatment of the person. This is to avoid disruptive appeals by unconnected third parties (such as representatives of lobby groups).
- Requirement of minimum of 2 working days between approval and administration of substance to allow for appeals

8. Planning and delivery of an assisted death

a. Advance decision for assisted dying

The Jersey Assisted Dying Citizens' Jury recommended that the law should provide for people to make an advanced decision to have an assisted death – this was the one Jury recommendation that was not brought forward in P95/2021.

Advance decisions are a mechanism via which people, with decision-making capacity, set out the types of care and treatment they do, or do not want, in the event they lack decision-making capacity at some point in the future, for example, if they are in a coma or lose capacity due to dementia. If advanced decisions were permitted for assisted dying this would allow a person to say, for example: "I want an assisted death if, at some point in the future, I have advanced dementia and I can no longer move, eat or speak". A majority (52.4%) of Citizen's Jury members were in favour of assisted dying being possible with an advance decision after losing capacity, but only under certain circumstances, however the recommendations report did not clarify the circumstances. Similarly, a number of people who participated in the Phase 1 public engagement process also supported advance decisions, particularly people who had lost a loved one due to dementia. Whilst there was a level of support for advanced directives, both the Jury members and those involved in Phase 1 engagement acknowledged the potential risks and difficulties associated for advance decisions in relation to assisted dying, for example:

- how can you be assured that someone still wants an assisted death if they cannot communicate with you, or if they can communicate but have lost decision-making capacity?
- how do you know a person has not changed their mind about an assisted death if there is a long period of time between an advance decision being made and the assisted death taking place?
- how can the assessment process be completed if the person does not have decision-making capacity both in terms of driving the process forward and ensuring the request is voluntary, clear, settled, and informed?
- how is it decided/who makes the decision as to the appropriate time for when the assisted death should take place, if the person does not have capacity to make this decision?

For these reasons neither the Phase 2 consultation proposals nor the report and proposition provided for advance decision on assisted dying, however, both set out proposals a waiver of final confirmation of consent (see below).

b. Waiver of final confirmation of consent

The report and proposition sets out that law will provide that a person who is eligible under Route 1 may make a 'Waiver of Final Confirmation of Consent'. This allows a person to decide in advance that, if they lose decision-making capacity AFTER their request for an assisted death has been approved (Step 5) but BEFORE they are due to confirm their consent during the 'final review' (at Step 7), the assisted death can still take place.

The Phase 1 consultation feedback showed limited support for a waiver overall, but of those who were supportive of the principle of assisted dying, 83% were supportive – i.e., there was strong support from those not opposed to assisted dying in principle. Feedback from the GMC commented on the sequencing of decision making and consent as it is set out in the Phase 2 consultation report proposals. The Phase 2 consultation proposals provided that signing of the waiver would take place prior to approval for an assisted death (Step 4 – Second Formal Request). These proposals have been updated in the report and proposition, reflecting the GMC feedback, to provide that signing of the waiver and any confirmation of consent to proceed would now take place after an approval has been granted, during the assisted death care planning phase (Step 6). As such, the 'Waiver of Final Consent' is now referred to as the 'Waiver of Final Confirmation of Consent'.

c. Confirmation of consent to proceed

The report and proposition provides that the person may provide 'Confirmation of consent to proceed', which allows the Administering Practitioner may take appropriate intervention in the event of complications during the process of administrating the assisted dying substance. For example, a person who has opted to self-administer the substance may loses decision-making capacity after digesting some but not all of the substance. In the circumstances, the 'Confirmation of consent to proceed' would allow the Administering Practitioner to proceed with administration of the assisted dying substance by IV. A person will be advised, but not required to provide confirmation of consent to proceed.

UK regulatory bodies, including the GMC indicated that the provision of confirmation of consent to proceed would not be inconsistent with their guidance (specifically, paragraph 31 of their decision making and consent guidance⁶⁴). The majority of survey respondents during the consultation were supportive of this (56% in agreement).

d. Administering the substance

P95/2021 set out that the law should allow for assisted dying either by 'physician assisted suicide' [now referred to as 'self-administration'] or by 'voluntary euthanasia' [now referred to 'practitioner-administration'].

As set out in report and proposition, the terminology has been updated to improve clarity and to align with the language used in other English-speaking jurisdictions, including New Zealand and Australia.

During the public consultation sessions, some participants stated that a person should have the choice of self-administration or practitioner-administration. Others took a view that if assisted dying is about personal choice and autonomy, the person must take the final step to end their life by self-administering the assisted dying substance. The middle ground view was that the substance should always be self-administered, except for when

⁶⁴ The dialogue leading to a decision part two of four - professional standards - GMC (gmc-uk.org)

the person is unable to self-administer, in which case it should be administered by the Administering Practitioner.

The Ethical Review reflected on the similarities and differences between the modes, noting that there are reasonable arguments in favour of, and against, both self-administration and practitioner-administration. The authors also stated that if the States Assembly considers the arguments about the two modes to be balanced, then it may judge it appropriate to provide for both modes of administration in law, with patients offered the choice of mode.

The Review went on to note, however, that the States Assembly may prefer to primarily allow for self-administration and to reserve practitioner-administration for exceptional cases, citing a number of reasons including the fact that "some [people] perceive a morally significant distinction between undertaking the act of administering fatal medication to another person, and (merely) providing the means by which the person can do this for themselves. As such, some believe that practitioner-administration more directly implicates the doctor in causing death".

The report and proposition allow for both self-administration and practitioner-administration, allowing the person to choose the most suitable method of administration for them, in consultation with the Administering Practitioner.

e. Support to self-administer the substance

The Phase 2 consultation asked if a loved one should be able to support a person to self-administer the substance, 50% responded 'yes', 37% 'no' and 13% 'don't know'. The Ethical Review commented on this proposal, noting that it seems appropriate to offer the person the option of having a (willing and able) loved one to be present and potentially even to assist.

Following feedback from the UK regulatory bodies, the report and proposition sets out that law will provide that where the person has chosen to self-administer the substance a family member or loved one may support them in the process, however, this may only be done under the direction of the Administering Practitioner.

f. Recording the cause of death

In some jurisdictions, for example Western Australia, the death certification process does not record the death as an assisted death; the cause of death is instead recorded as the underlying illness which the person had which made them eligible for an assisted death. In other jurisdictions, however, the law and associated guidance strives for transparency and acceptance around the assisted dying process, for example, in New Zealand and Canada, where the death is recorded as an assisted death with the underlying illness also being noted as a factor.

The Phase 2 consultation proposed that, in Jersey, assisted deaths should be recorded in the same way as all other deaths in Jersey. This proposal received broad support — with 77% of respondents agreeing that the Medical Certificate of the Fact and Cause of Death ("MCFCD") should accurately record the cause of death, which would include reference to the administration of the assisted dying substance as a antecedent cause of death.

Respondents who were not supportive of this approach noted the potential impact on the families of people who have had an assisted death, where they do not want this to be known, as this information will be in the public domain. The Ethical Review considered the matter, noting that the arguments for clear, consistent, and accurate reporting appear to be strongest. The Review authors also noted that the current proposals include provision for clear guidance and training for those completing the MCFCD.

Planning and delivery of an assisted death: Summary of key changes / clarifications

- The law will provide for a 'Waiver of Final Confirmation of Consent' to allow for an assisted death to proceed if the person loses decision-making capacity AFTER their request for an assisted death has been approved but BEFORE they are due to confirm their consent prior to administration of the assisted dying substance
- The law will provide for a 'Confirmation of Consent to proceed' allowing the Administering Practitioner may take appropriate intervention in the event of complications during the process of administrating the assisted dying substance.
- The law will permit both self-administration and practitioner administration of the assisted dying substance.
- A family member or loved one may support the person to self-administer the substance but only under the direction of the Administering Practitioner.
- An assisted death to be recorded in the same way as other deaths in Jersey.
 This means that use of assisted dying substance will be a matter of public record.

9. Regulation and oversight

Phase 2 proposals set out that the Jersey Assisted Dying Service should be inspected and regulated by the Jersey Care Commission ("JCC"). This position was informed by detailed discussion with the Professional Leads working group and UK professional regulatory bodies (GMC, NMC etc.) and learning from other jurisdictions.

The Phase 2 consultation survey response was supportive of this approach with 62.9% of respondents agreeing that the JCC should independently regulate and inspect the service.

The Regulation of Care Law currently provides that the JCC may cancel the registration of a service provider who fails to comply with conditions imposed on them by the JCC unless that service is 'essential' (i.e., the Minister is the sole provider of that service). The Phase 2 proposals set out that the Regulation of Care Law should be amended to ensure that the Assisted Dying Service falls outside of the definition of an essential

service – therefore enabling the JCC to suspend or cancel the Service's registration which effectively shuts the Service down – if the JCC were to find significant failings. Feedback to these proposals was mixed, with 47.7% of survey respondents in agreement and 42.6% disagreeing. Those in agreement felt that providing the JCC with the power to suspend / cancel the service was an essential safeguard; those who disagreed expressed fears of interference with the democratic process (i.e., thwarting the decision of the Assembly to provide for an Assisted Dying Service) and the impact on those who were seeking an assisted death at the time of the cancellation of registration.

Reflecting on that feedback, the report and proposition sets out that the law will provide for the JCC to suspend or cancel the registration – thereby effectively shutting the service down – but that this will only extend to preventing the service from assessing and approving new or ongoing requests on an assisted death. Where there is an existing approval, the person may still proceed to have an assisted death, unless the JCC's grounds for suspension / cancellation rest with individual practice of either the Coordinating Doctor and / or Independent Assessment Doctor of those specific persons.

Regulation and oversight: Summary of key changes / clarifications

- The law will provide that the Assisted Dying Service will be regulated and inspected by the Jersey Care Commission (JCC).
- The law will provide that the JCC may cancel the registration of the Service, but in doing so this will not prevent a person whose request is approved from having an assisted death unless the JCC's concern relate to individual practice of either the Coordinating Doctor and/or Independent Assessment Doctor of that person.

Appendix 2: List of safeguards and case studies

Part 1: list of safeguards

Safeguarding objectives

- 1. There are five key safeguarding objectives. To ensure:
 - i. only those who meet the eligibility criteria set out in law are approved for an assisted death
- ii. all islanders are protected and supported throughout the assisted dying process, including:
 - a. Islanders who may be coerced or pressured into requesting assisted dying
 - b. people with mental health conditions and / or those who do not have decision-making capacity
 - c. family members and loved ones of the person requesting an assisted death
 - d. continuing ongoing support, care and treatment for person whilst requesting an assisted death and on the assisted dying process
- iii. assisted dying practitioners act in accordance with guidance and law
- iv. professionals are supported and protected when acting in accordance with guidance and law, regardless of their position on assisted dying
- v. Jersey Assisted Dying Service is safe and of high quality.
- 2. The safeguard associated with each of those objectives is described below. There is significant overlap between objectives.

Safeguarding objective 1: Eligibility criteria compliance

- 3. There are clear eligibility criteria set out in law including:
 - Jersey residents only
 - voluntary, clear, settled and informed request
 - decision-making capacity [with no provision for advance requests]

- medical eligibility criteria 'Route 1 terminal illness' or 'Route 2 unbearable suffering'
- 4. There are no broad Regulation making powers to amend the criteria, any future changes would require a primary law change.
- 5. There is a requirement for two assessments by two doctors to ensure compliance with eligibility criteria. The assessments are independent of each other. There is further confirmation by Tribunal for 'Route 2 unbearable suffering'.
- 6. The assessing doctors are required to ensure that the person is aware of all other treatment and care options, prior to confirming the person's eligibility for assisted dying.
- 7. The multi-disciplinary team (MDT) and additional assessments / additional clinical opinions are required where an assessing doctor is not able to reach a determination about elements of the eligibility criteria, including:
 - the decision-making capacity of person; this can include additional assessment by social worker, nurse or psychological / psychiatric assessment etc, where appropriate
 - the request is voluntary, clear, settled and informed: this can include additional assessment by social worker or information from other agencies, where appropriate (in addition to discussion with family and friends)
 - eligibility on medical grounds e.g. prognosis: this can include advice or assessment by a treating consultant or consultant with expertise in that medical condition. Where the person is eligible under 'Route 2 unbearable suffering' the law will set out that the Coordinating Doctor must seek opinion from a professional who does have expertise in the person's condition, unless the Coordinating Doctor is satisfied that the Independent Assessment Doctor has sufficient expertise.
- 8. The person has right to request an additional assessment by Second Opinion Doctor.
- 9. There is provision for appeal to the Royal Court, by the person and those with special interest in the person's health and care. The grounds for appeal are limited but include elements of the eligibility criteria (residency, capacity, voluntariness of decision).

Safeguarding objective 2: Protecting and supporting all islanders

- 10. Jersey Assisted Dying Service will provide information and support for all Islanders on assisted dying, including online and printed information materials.
- 11. The person requesting assisted dying can self-refer to the Jersey Assisted Dying Service or be referred by a healthcare practitioner. Their ability to access the Service is not restricted by a professional referral requirement.
- 12. The law will allow the practitioner to raise subject of assisted dying, which helps supports equality of access. There will be training and guidance for all heath care practitioners to support *appropriate* conversations around assisted dying.
- 13. There will be provision for interpreters / communication and / or advocacy to support a person who has requested assisted dying.
- 14. The law acknowledges that a person has right to privacy family members or other attending practitioners or carers do not have to be informed of a person's assisted dying request however, the person is *encouraged* to notify family and other attending practitioners or carers. It must be explained to the person that their right to not inform others might impact an assessing doctor's ability to determine eligibility.
- 15. The pace and progression of the request, assessment, approval and delivery process is determined by the person, who must request to move on to each step of the process and has right to pause or slow the process, or withdraw their request at any point.
- 16. Minimum timeframes a period of reflection is built into process, from first formal request to final consent to proceed. These are 14 days for 'Route 1 terminal illness' or 90 days for 'Route 2 unbearable suffering'
- 17. The 14-day timeframe for Route 1 may be waived IF person has life expectancy of less than 14 days, to prevent further suffering to person, however person must still be fully assessed and meet all the eligibility criteria to be approved for assisted dying.
- 18. The person requesting assisted dying must demonstrate decision-making capacity throughout the process, and must also demonstrate that their request for an assisted death is voluntary, clear, settled and informed.
- 19. The MDT and additional assessments / clinical opinions are available to the assessing doctors to support a determination of:
 - the decision-making capacity of the person including additional psychological / psychiatric assessment, if person's presentation or medical

- history suggests their mental health may impact on their decision-making capacity
- the nature of the request i.e., that it is voluntary, clear, settled and informed (for example, an MDT social worker may undertake an assessment to explore possibility of pressure or coercion).
- 20. The assessing doctors are required to ensure the person is aware of all other treatment and care options, prior to confirming eligibility for assisted dying.
- 21. The Assisted Dying Person Record (i.e., the single record for each person requesting an assisted death) ensures that all information relating to the request is held securely and confidentially in one place.
- 22. The person's ongoing care and treatment continues throughout the process and is not affected by their request for an assisted death. This includes, but is not restricted to, any palliative or end of life care and treatment they are receiving.
- 23. There will be signposting and support for those who are assessed as not eligible for assisted dying, including onwards referral to specific services if any safeguarding concerns or additional social care needs are identified.
- 24. The person's wishes for their assisted death (for example, place of death and mode of administration) are discussed throughout assessment process and confirmed in the in the Assisted Death Care Plan. This includes matters related to presence and / or involvement of family and loved ones.
- 25. The person can provide advanced consent not to receive life-saving treatment (e.g., resuscitation), and also provide advanced consent to the administration of additional assisted dying substance in the event of medical complications such as regurgitation, vomiting or seizures.
- 26. A Waiver of Final Confirmation of Consent allows a person's assisted death to proceed if they lose decision-making capacity after approval of their assisted dying request but before delivery of an assisted death, however:
 - if a Waiver is not in place, and person has lost decision-making capacity, the assisted death cannot proceed
 - If a Waiver is in place but person is showing signs of refusal or resistance at the point of administration, the assisted death cannot proceed.
- 27. There is no expiry of the approval for an assisted death to ensure that pressure is not placed on the person to end their life if they are not ready to do so.

- 28. The Administering Practitioner, and the other professional present at the delivery of assisted death, oversee the administration of medication and are present to deal with any complications that may arise. The presence of two professionals enables support to be provided to any family members or loved ones who are in attendance.
- 29. Family members and friends may access wellbeing and bereavement support.
- 30. The Assurance and Delivery Committee oversees clinical governance and service safety and quality.

Safeguarding objective 3: Practitioners act within the law

General

- 31. Health professionals have to 'opt in' to working for the Jersey Assisted Dying Service, which must maintain an up to date registered of those professionals. They must all have undergone mandatory training prior to registration which will include training on legal provisions. Training must be renewed every three years.
- 32. The Jersey Assisted Dying Service will be regulated and inspected by the Jersey Care Commission. This will ensure independent oversight of compliance with service standards and legal provision.
- 33. The law will provide a range of offences that act as deterrent to anyone who intentionally acts outside of the law (this includes professionals and other people, for example family members). Offences include, for example, administering an assisted dying substance if you are not authorised to do, or making a false statement. The offences would not apply to a professional who unknowingly carries out an act in good faith.
- 34. Involved professionals must complete a declaration of interest form to confirm they are not related to the person making a request for an assisted death, nor set to gain from their death (e.g., a beneficiary of their will)

Request, assessment and approval

35. There are two separate assessments carried out by two assessing doctors (who are trained to provide individual clinical judgement on eligibility). The assessments are independent of each other. The Independent Assessment Doctor may not see First Assessment Form until they have completed their independent assessment. However, they may access any opinions or supporting assessments requested by the Coordinating Doctor to avoid duplication.

- 36. The MDT will provide legitimate professional challenge to the assessing doctor's decision-making. This will help improve practice, provide cross-discipline consideration and ensure assessments are not reliant on a 'lone doctor'.
- 37. Additional assessments or clinical opinions are required where an assessing doctor is not able to make a determination about:
 - the decision-making capacity of person
 - the voluntary, clear, settled and informed nature of request
 - eligibility on medical grounds e.g. prognosis.
- 38. The Second Formal Request form must be signed by the person and the Coordinating Doctor in the presence of an independent witness, who knows the person sufficiently well to be able to attest to the fact that they are acting freely in making their second request.
- 39. The Coordinating Doctor must undertake an administrative review after completion of both assessments to ensure all documentation is complete and all steps in the process have been complied with prior to making a final approval decision. Where the request is approved under 'Route 2 unbearable suffering' the Coordinating Doctor's approval decision must be confirmed by the Tribunal.
- 40. A post-death review will be undertaken for every assisted death to determine adherence to guidance and legislation.
- 41. The Assisted Dying Person Record will be a singular record management system for all assisted dying requests, assessments and other recorded information, enabling better oversight and governance across the Service, including oversight of caseloads of individual assisted dying professionals, which may be reviewed by the Assisted Dying Review Panel.

Delivery of assisted death

- 42. The Prescribing and Dispensing Guidance ensures a clear chain of responsibility over the assisted dying substance from pharmacy to administration of substance.
- 43. Administering Practitioner and an administration witness will be present at the assisted death i.e., there is no lone practitioner. The administration witness will be another member of the Jersey Assisted Dying Service who can also support the Administering Practitioner in clinical matters (e.g.: setting up IV lines) if they are clinically qualified to do so.

- 44. The person must provide final consent prior to administration of substance, which will be recorded on the Final Consent and Review form.
- 45. The Administering Practitioner will carry out a final review prior to administration of substance. If the person does not have capacity (and no Waiver of Final Confirmation of Consent is in place) or the person is not making the decision voluntarily, the assisted death cannot proceed. If Waiver of Final Confirmation of Consent is in place but the person is showing signs of refusal or resistance, the assisted death cannot proceed.
- 46. The person will have made a decision in the Assisted Dying Care Plan whether to provide advance consent not to receive life-saving treatment (e.g., resuscitation), and consent to for the Administering Practitioner to administer additional assisted dying substance in the event of medical complications. This provides clarity to the Administering Practitioner as to what actions can be taken in the event of medical complications.
- 47. The administration witness will be required to certify that they witnessed the Administering Practitioner administer the assisted dying substance to the person (this will be recorded on the post-death administration form).

Post-death and governance

- 48. A Medical Certificate of Fact and Cause of Death (MCFCD) must be completed by a qualified Registered Medical Practitioner (RMP). The RMP is a doctor who is independent of the Jersey Assisted Dying Service and who attended the person within 14 days prior to their death.
- 49. The post-death review, which must be undertaken after all assisted deaths, can support the Assisted Dying Review Panel to identify concerns or suspected malpractice.
- 50. Role of Assurance and Delivery Committee to:
 - oversee establishment of service (development of training & protocols)
 - oversee delivery of Jersey Assisted Dying Service including:
 - development of, and assurance of compliance with, clinical standards
 - o development service standards, including target maximum timeframes for the Jersey Assisted Dying Service
 - o oversight of service safety and quality, through continuous monitoring of the service

- o oversight of the management and response to complaints and / or potential patient safety concerns related to the service
- o providing assurance to the Minister and the public about patient experience, clinical safety and service quality
- o approving the retention schedule for all records held by the Jersey Assisted Dying Service
- producing and publishing an annual report on assisted dying in Jersey
- o establishment of an Assisted Dying Review Panel
- 51. In the event of safety concerns, the Assisted Dying Complaints and Concerns Policy will set out the procedures for responding to concerns, both in term of HCS processes and any escalation to the JCC or the relevant UK professional regulatory body, in the instance of fitness to practise concerns.
- 52. Jersey Care Commission (JCC) to register the Jersey Assisted Dying Service and inspect the Service at least once every 12 months, including the option to carry out unannounced inspections. The JCC will have powers to cancel registration in the event of significant failures to comply with any conditions imposed on the Service.
- 53. Assisted Dying Assurance and Delivery Committee must publish the Assisted Dying Complaints and Concerns Policy setting out clear processes for complaints and concerns by service users, or their family and other professionals

Safeguarding objective 4: Practitioners are supported and protected when acting in accordance with guidance and law

- 54. The law will provide a right for health professionals to refuse to directly participate in assisted dying on any grounds, including conscientious objection.
- 55. Health professionals have to 'opt in' to working for the Jersey Assisted Dying Service via the registration process. They cannot be compelled to register.
- 56. There will be wellbeing and peer support for all assisted dying practitioners and all other attending practitioners and carers (i.e., those professionals who are caring for a person who requests assisted dying but are not involved in the process).
- 57. Assisted Dying Assurance and Delivery Committee to produce clear guidance on all aspects of process. This will be developed in consultation with key bodies, including UK professional membership and regulatory organisations who have oversight of the professional's practice.

- 58. All assisted dying practitioners will need to undergo mandatory training, including members of the MDT. This will ensure they have the knowledge to work in the service. Training and guidance will also be available to all other health care practitioners, this will provide an outline of the law and the assisted dying process, including matters related to referral and appropriate conversations.
- 59. A witness required for person's Second Formal Request for assisted dying, confirms voluntary, clear, settled and informed nature of person's request

Delivery of Assisted death

- 60. Where the death takes place in a private residence, the Administering Practitioner must be accompanied by another professional (the administration witness) who will attend the delivery of the assisted death. The Administering Practitioner will not be a "lone operator".
- 61. The person will, in most cases, have made a decision whether to provide advance consent not to receive life-saving treatment (e.g., resuscitation), and advance to consent to the administration of additional assisted dying substance in the event of medical complications. This provides the Administering Practitioner with clarity as to the person's wishes and what actions can be taken in the event of complications.
- 62. The person must provide final consent prior to administration of substance via Final Consent and Review form with an independent witness (member of MDT)

Post-death and governance

- 63. Post-death assisted dying review of each death to determine whether, in each case, practitioner has acted with adherence to the legislation and guidance
- 64. Assisted Dying Review Panel to review:
 - i. each assisted death
 - ii. a sample of assisted death requests that did not progress to an assisted death
 - iii. In order to determine:
 - proper adherence to the legislation and guidance
 - identify any process matters that may require improvement / change

Safeguarding objective 5: High-quality, safe service

Request, assessment and approval

- 65. Jersey Assisted Dying Service provides clear written information to Islanders (including healthcare professionals) on assisted dying, including online and printed information materials
- 66. Jersey Assisted Dying Service is overseen by a dedicated, independently chaired, Assisted Dying Assurance and Delivery Committee. The Committee's role will include:
 - approval of guidance and protocols
 - ensuring robust clinical governance
 - ensuring oversight of service safety and quality
- 67. The Multidisciplinary Team provides a collaborative forum for determination of assessments and related matters and supports the assessing doctors to make informed decisions
- 68. The Assisted Dying Person Record provides a singular record management system for all assisted dying requests, assessments and other recorded information, enabling better oversight and governance in each case.
- 69. Assessment Guidance will provide that assessment meetings should, as a matter of standard practice, should be in-person (i.e., not remote assessments via video link etc) with remote meetings and consultation by exception only (for example, a follow up consultation to discuss a particular issue).
- 70. The Assisted Dying Assurance and Delivery Committee will publish an Assisted Dying Complaints and Concerns Policy setting out a clear process for complaints and concerns by service users, or their family and other professionals. They will also monitor compliance against that policy.

Delivery of Assisted death

- 71. The Assisted Death Care Plan, completed by the Administering Practitioner in dialogue with the person will set out all matters related to the delivery of the assisted death, including
 - the location (all locations must be pre-approved as suitable for an assisted death)
 - mode of delivery (i.e., practitioner administered or self-administered with or without the support of family members)

- other key details, including who will be present
- 72. The Prescribing and Dispensing Guidance and Assisted Dying Substance Administration Guidance will ensure a clear chain of responsibility over the assisted dying substance from preparation and dispensing at the hospital pharmacy to administration of the assisted dying substance, and safe disposal of any unused substance.
- 73. The Administering Practitioner, and the other professional present at the delivery of assisted death, oversee the administration of medication and are present to deal with any complications that may arise.

Regulation

- 74. The Assisted Dying Review Panel must undertake a post-death review of every assisted death to determine adherence to guidance and legislation, identify trends and opportunities for service improvement.
- 75. The Assurance and Delivery Committee will publish an Assisting Dying Annual Report setting out matters related to the numbers of requests, names of assisted death etc. This will include information related to demographic details, types of health condition etc. All data will be published anonymously. The Medical Officer for Health will act as an independent adviser to agree the data to be presented in that annual report and to agree the methodology for compiling the data
- 76. The Jersey Assisted Dying Service will be registered and regulated by the Jersey Care Commission who: must undertake annual inspections of the Service; may undertake any number of unannounced inspections; will be provided powers to sanction or suspend the Service.

Part 2: Assisted Dying safeguards – possible scenarios, case studies

- 1. The case studies below illustrate how safeguards will apply in different circumstances:
 - Person 1: vulnerable elderly, possible coercion
 - Person 2: right to privacy, complications with administration of substance
 - Person 3: learning disability, dementia, capacity concerns
 - Person 4: end stage of life, impact on pace/progression of process, Waiver of Final Confirmation of Consent

- Person 5: possible coercion, history of domestic abuse, impact of mental health on capacity
- Person 6: mental health diagnosis and capacity
- Person 7: possible coercion due to inheritance considerations
- Person 8: mental health diagnosis and capacity, 'Route 2' request
- Person 9: vulnerable elderly, no immediate family, 'tired of life' request
- Person 10: mental health diagnosis (anorexia) and capacity, second opinion request
- 2. These case studies are hypothetical and have been developed to demonstrate how safeguards will operate around the Jersey Assisted Dying Service, any similarity to actual events or persons is coincidental.
- 3. There are standard parts of the process, which apply in all cases, which are not set out in detail in all the case studies (for example, the second formal request is always signed by a witness). This is to avoid repetition.

Person 1

- Jean aged 72, widowed, 3 adult children (2 UK based, 1 in Jersey)
- Lives in annexe of eldest daughter's family home in Jersey
- Diagnosed with terminal lung cancer 2 months ago, after 3 unsuccessful rounds of chemo/radiotherapy
- In receipt of domiciliary palliative care

Possible safeguarding considerations

- Coercion from family to seek assisted death to ease care burden
- Jean is worried about being a 'burden' on her daughter, who has a young family and is already caring for Jean

Circumstances / sequence of events

- Jean seeks appointment with her long-term GP to discuss assisted dying. Jean's GP is a registered assisted dying practitioner in Jersey. Jean's daughter is in attendance.
- GP completes an initial enquiry form and refers Jean to the Jersey Assisted Dying Service. He tells Jean he is willing to be her Coordinating Doctor should she wish to proceed with a formal first request. (Her GP is a registered assisted dying practitioner)
- On receiving the initial enquiry form, the Care Navigator contacts Jean, who confirms she wishes to make an appointment to make a first formal request.
- Jean makes first formal request to the Coordinating Doctor (who is her GP). She asks that she is assessed for an assisted death as soon as possible.
- During the first assessment process, which includes multiple meetings with the
 Coordinating Doctor, Jean discusses her wish for an assisted death and
 mentions a documentary on the subject she watched with her daughter. She
 explains that she had not previously considered assisted dying but, in the weeks
 since seeing the documentary she has given the matter a great deal of thought
 and is confident in her decision.
- During the first assessment they discuss her treatment and care options, including options for further chemotherapy.

- The Coordinating Doctor confirms with Jean's consultant that her diagnosis is terminal and life expectancy is less than 6 months.
- A social worker (as part of the assisted dying multi-disciplinary team) explores the potential for coercion. The social worker speaks with Jean about family dynamics, and then speaks separately with close family members. Jean has given permission for the social worker to speak with other family members.
- The social worker determines that the family is supportive of Jean's decision, but that Jean is making the decision voluntarily and without coercion.
- The Coordinating Doctor assesses Jean as meeting the 'Route 1' eligibility criteria.
- The next week Jean decides to pause the process and undergo an additional round of chemotherapy as suggested by her consultant. [As with all persons requesting assisted dying, all care and treatments should continue regardless of the assisted dying request.]
- After 2 weeks, Jean makes the decision to:
 - a. stop chemotherapy, given the level of pain and suffering she is experiencing, and on the understanding that the treatment would likely not prolong her life for more than a month, and
 - b. continue with the assisted dying process by requesting that her second assessment takes place.
- Independent Assessment Doctor, who has not previously met Jean, reviews the supporting social worker assessments requested by the Coordinating Doctor, then carries out a separate full independent assessment with Jean. The Independent Assessment Doctor also determines that Jean meets the eligibility criteria.
- The Coordinating Doctor meets with Jean who makes a second formal request for assisted dying, signed by an independent witness.
- Given the progression of her disease he explains Jean may wish to sign a Waiver of Final Confirmation of Consent so that the assisted dying may proceed if Jean loses decision-making capacity after receiving approval for assisted dying but before the assisted death taking place.
- The Coordinating Doctor completes the Administrative Review and approves Jean's request for an assisted death. Jean is informed she may proceed to the

- planning stage for her assisted death, when she chooses to (allowing for a minimum of two working days before the assisted death in the event of any appeal).
- Earlier in the assessment process the Coordinating Doctor had also offered to carry out the role of Administering Practitioner, which Jean chooses to accept.
- Jean requests an Assisted Death Care Plan meeting with the Administering Practitioner, with her daughter in attendance. Jean decides that she wants:
 - her assisted death, at home, with close adult family members in attendance
 - o to make a Waiver of Final Confirmation of Consent
- The Administering Practitioner and an MDT nurse arrive at Jean's home on the agreed date/time. The Administering Practitioner carries out final review of Jean's capacity, and her request for an assisted death checking that her decision is voluntary, settled and informed.
- The Administering Practitioner determines that Jean still has capacity so there
 is not requirement for the Waiver of Final Confirmation of Consent to be relied
 on
- Jean decides she would like her daughter to support her to take the assisted dying substance even though this was not specified in the Assisted Death Care Plan. Her daughter agrees and the Administering Practitioner explains to the daughter how to support her mum, and that the administration can only be carried out under his direction this is all recorded on the Final Consent and Review Form. The nurse acts as a witness to this.
- Jean is supported by her daughter to self-administer the assisted dying substance orally and loses consciousness a few minutes later, the Administering Practitioner stays nearby, though in a different room at the request of Jean, as recorded in her Assisted Death Care Plan and agreed with the family.
- The Administering Practitioner checks on Jean frequently and records her death 23 minutes after ingesting the substance. The Administering Practitioner completes the Post-Assisted Death Administration Form, this includes details of the substance administered, time of administration and time of death, any medical complications or interventions taken.

Summary of key safeguards

- Assessment by 2 independent assessing doctors
 - o GP knows family and has an understanding of the family dynamics
 - balanced by Independent Assessment Doctor who has not previously treated Jean
 - both assessing doctors must complete a declaration of interest form to confirm they are not related to person making request, nor set to gain from their death (e.g., a beneficiary of their will)
- Multidisciplinary team (MDT)
 - additional social worker assessment considers family dynamic and rules out risk of coercion / request for assisted dying not being voluntary
- Assisted Dying Person Record records all assisted dying information
 - allows for an update to the Assisted Death Assisted Death Care Plan (i.e. daughter supports Jean to self-administer), this change is noted on the Final Consent and Review form.
- Pace and progression driven by the person
 - Jean decided to pause the process for further chemotherapy, but then resumed process after 2 weeks – opportunity to slow or pause process to further explore all treatment/care options.
- Continued care and treatment
 - o Jean continues to be able to access treatment (i.e., further chemotherapy) whilst progressing with her assisted dying request
- Waiver of Final Confirmation of Consent
 - o in place, though not required in this case
- Administering Practitioner present throughout delivery of assisted death oversees administration of medication
 - o daughter able to support Jean to ingest substance but under medical guidance of Administering Practitioner

Person 2

- Robert, 84, married, 2 grown children (both live in UK)
- Lives with wife in private residence
- Diagnosed with end stage COPD (Chronic obstructive pulmonary disease)
- Wife is opposed to assisted dying
- In receipt of domiciliary palliative care

Possible safeguarding considerations

- Robert does not want to inform family member of his request.
- Wife not supportive of Robert's wishes for end of life.

Circumstances / sequence of events

- Robert mentions his wish for assisted dying to his palliative care nurse, who
 refers him to the Jersey Assisted Dying Service.
- Robert speaks with the Care Navigator and is assigned a Coordinating Doctor.
- During his first appointment with the Coordinator Doctor, Robert makes his first formal request for an assisted death. He also tells the Coordinating Doctor that his wife is opposed to assisted dying so he does not want her to know about his request. This is noted in his assisted dying record by the Coordinating Doctor who explains to Robert that he has the right to keep his request and assessment confidential but not being able to speak with key family members may hinder both the Coordinating Doctor's and the Independent Assessment Doctor's ability to determine if Robert is eligible for assisted dying, on the basis that they may not be able to determine if his wish is voluntary, clear, settled and informed.
- Robert decided he wishes to proceed to the next step and requests a first assessment. During the first assessment process Robert further discusses his wife's views, which are based on her strong religious convictions, and

- confirms to the Coordinating Doctor that he does not want her to be made aware of his request.
- They also discuss Robert's treatment and care options and the fact that he has a terminal diagnosis with life expectancy of less than 6 months. The Coordinating Doctor determines Robert has decision-making capacity and is of the view that Robert's wish for assisted dying is voluntary, clear, settled and informed but decides to seek further professional opinion to confirm this.
- A social worker carries out an additional assessment with Robert and his
 daughter, who is visiting the island and who Robert has confided in. Having
 spoken with Robert and his daughter, the Social Worker confirms they are
 also of the view that Robert's request is voluntary, clear, settled and
 informed.
- Coordinating Doctor determines that Robert meets the eligibility criteria set out in law, under 'Route 1'.
- The next week the Independent Assessment Doctor reviews supporting assessments requested by the Coordinating Doctor, then carries out a separate , independent assessment. The Independent Assessment Doctor also determines that Robert meets the eligibility criteria.
- The Coordinating Doctor meets with Robert who makes a second formal request for assisted dying, signed by an independent witness.
- The Coordinating Doctor completes the Administrative Review, approves Robert's request for assisted dying and informs Robert he may proceed to the planning stage for his assisted death
- Robert and the Administering Practitioner meet to discuss his Assisted Death Care Plan. Robert is accompanied by daughter, who has extended her stay on-island.
 - o Robert wants to self-administer the substance
 - The Administering Practitioner talks through the details of selfadministration including the potential complications
 - Robert consents to the Administering Practitioner administering additional medication to complete the assisted death in the event of any complications with self-administration

- They have a detailed discussion about the fact that Robert's wife still
 does not know about his request. Robert makes the decision to tell his
 wife with the support of his daughter
- Robert informs his wife, who is shocked. Whilst she acknowledges his
 extreme suffering, she cannot accept his decision. The Care Navigator
 contacts Robert's wife and offers her access to a counselling and support
 service, which she accepts.
- A few days later Robert meets again with the Administering Practitioner to finalise the Assisted Death Care Plan.
- The Administering Practitioner and MDT nurse attend Robert's home on the agreed date and time. Robert's daughter is also in attendance. The Administering Practitioner carries out a final review and Robert is assessed as having capacity and making a voluntary, clear, settled and informed request, this is recorded on the Final Consent and Review form.
- As a precaution (and as Robert had consented to it in his Assisted Death Care Plan) he has an IV inserted prior to taking the assisted dying substance orally.
- Robert is supported to self-administer orally but struggles to swallow the substance. He nevertheless loses consciousness a few minutes later.
- The Administering Practitioner checks on Robert frequently, however he still has a pulse after 60 minutes. In accordance with the guidance produced by the Assurance and Delivery Committee, and with Robert's prior consent, the Administering Practitioner administers an additional dose of the substance intravenously. There are no further complications, and 4 minutes later the Administering Practitioner confirms Robert's death.
- This is recorded in the Final Consent and Review Form, including the assisted dying substances given, dosage and time to death.
- During the post-death review, the Assisted Dying Review Panel give detailed
 consideration to: the length of time it took Robert to die; whether the
 necessary consent was given for IV administration; whether the
 Administrating Practitioner should or could have taken a different course of
 action. The review concludes that there were no errors and the care provided
 to Robert accorded with standards.

Summary of key safeguards

• Right to privacy

- Robert has a right to privacy he understood that whilst his wife did
 not have to be informed of his request, his decision might impact on
 the assessing doctors' ability to determine eligibility.
- Pace and progression driven by the person
 - This allowed Robert the time and space necessary to help him decide that he would discuss his wishes with his wife. As a result, the Assisted Death Care Planning process took place over 2 separate meetings a number of days apart.
- In event of medical complications, option to consent to IV administration in Assisted Death Care Plan
 - Administering Practitioner discuss process and risks involved in administration of assisted dying substance. Robert was clear he wanted to self-administer, but also aware of possible complications and willing to consent to IV administration, if required.
- Support for family members
 - Access to counselling / support services via Jersey Assisted Dying Service for Robert's wife
- Assisted Dying Delivery and Assurance Committee; development of guidance and protocols
 - Clear protocol were in place for the Administering Practitioner to follow in the event of medical complications, including delayed death following oral ingestion of the assisted dying substance.
- Post-death review
 - External review focussed on the delivery of the assisted death, and whether the steps taken by the Administering Practitioner were appropriate and in line with the law and guidance.

Person 3

- Sean, 59, single, no children, 1 elderly sister who lives in Jersey
- Lives in supported housing run by Les Amis
- Has a moderate learning disability and has recently been diagnosed with vascular dementia
- Not in receipt of palliative care

Possible safeguarding consideration

• Sean may not have decision-making capacity to request an assisted death, either due to his learning disability or the disease progression of dementia.

Circumstances / sequence of events

- Sean lives in supported accommodation; he is able to express his views and wishes fluently. His learning disability impacts on his social and emotional interaction with others.
- Sean attends a GP appointment regarding his dementia diagnosis. His care worker also attends at Sean's request.
- At the appointment Sean expresses his concerns about the future and the impact dementia could have on him. Sean does not use the term 'assisted dying' but talks to the GP about his cousin in Australia who the doctor helped to die when he got terminal cancer. Sean says he wants the same thing.
- The GP explains the term assisted dying and the associated eligibility criteria. He also explains that, given Sean is likely to live much longer than 6 months, and that he does not feel Sean is currently experiencing 'unbearable suffering', it is unlikely that Sean will meet the criteria. He nevertheless offers to refer Sean to the Jersey Assisted Dying Service.
- A Care Navigator meets with Sean and his care worker to provide more information about assisted dying. Sean asks to see a Coordinating Doctor so that he can make his first formal request.
- At a meeting with the Coordinating Doctor, the Coordinating Doctor also explains the eligibility criteria and informs Sean he may not be found eligible. Sean nevertheless wants to proceed.

- A specialist learning disability nurse from the MDT is asked to assess Sean's decision-making capacity. Sean is found to have the capacity to:
 - o understand information or advice about an assisted dying decision
 - o understand the matters involved in an assisted dying decision
 - o understand the effect of an assisted dying decision
 - weigh up the factors referred to above for the purposes of making an assisted dying decision
 - communicate an assisted dying decision.
- As Sean has decision-making capacity, the Coordinating Doctor and Sean sign the First Formal Request form. Sean then requests to proceed to the First Assessment process.
- As part of the First Assessment process, the Coordinating Doctor confirms with Sean's Consultant that Sean's life expectancy is more than 6 months.
- The Coordinating Doctor further discusses with Sean his wish for an assisted death and Sean's current level of suffering. Sean states that he is not currently in pain or suffering but is scared about what dementia is and how he will be in the future.
- Coordinating Doctor determines that Sean does not meet the eligibility criteria under 'Route 1 terminal illness' as Sean has more than 6 months to live, nor under 'Route 2 unbearable suffering' as Sean is not currently experiencing unbearable suffering.
- The Coordinating Doctor meets with Sean to explain the outcome of the assessment. Sean decides not to request a Second Opinion Assessment
- Coordinating Doctor signpost Sean and his care worker to additional support including from Dementia Jersey.

Summary of key safeguards

- The Law allows practitioner to raise subject of assisted dying
 - o Although Sean does not use the term 'assisted dying' he clearly wanted to discuss the subject. The law did not prohibit the GP from

explaining the term, which the GP did in accordance with the published Appropriate Conversations guidance.

- MDT and specific capacity assessment
 - The MDT included a nurse with a specialism in learning disabilities who carried out a capacity assessment
- Option for second opinion assessment
 - Sean was assessed as ineligible for assisted dying, but was offered the option of a second opinion assessment, which he declined
- Signposting for additional support
 - Sean's request for assisted dying was motivated by fears and concerns around his dementia diagnosis. Whilst ineligible for assisted dying, Sean was signposted to additional support

- Claire is 42 years old, married with 3 children under 10 years old
- Lives in a private residence with her family
- Has been recently diagnosed with stage 4 metastatic breast cancer
- In receipt of residential palliative care (at a Hospice)

Possible safeguarding considerations

• No specific concerns but Claire is at the end stage of the disease which may have an impact on pace and progression of the assisted dying process.

- Claire is close to the end of life and experiencing a great deal of pain and suffering.
- At her request, Claire's husband directly contacts the Jersey Assisted Dying Service. A Coordinating Doctor is assigned, and Claire states she wishes to make a first formal request during a video call. The Coordinating Doctor then attends Claire at the Hospice and she signs the First Formal Request form in person. She requests the assessment process to begin as soon as possible.
- The Coordinating Doctor attends Claire again to start the assessment process. During the appointment the Coordinating Doctor assesses Claire's decision-making capacity and whether her wish for an assisted death is voluntary, clear, settled and informed. The Coordinating Doctor determines she meets the criteria and informs Claire. The Coordinating Doctor is of the opinion that Claire has less than 14 days to live.
- Independent Assessment Doctor carries out separate assessment with Claire two days after the first assessment. The Independent Assessment Doctor also determines that Claire meets the eligibility criteria and that her life expectancy is less than 14 days.
- On the same day the Coordinating Doctor meets with Claire who makes a second formal request for assisted dying, signed by an independent witness.
- The Coordinating Doctor then completes the Administrative Review and Claire is informed that her request is approved and that she may proceed to

- the planning stage for her assisted death, given her short life expectancy, she is not required to wait the full 14 days prior to having the assisted death.
- The Coordinating Practitioner agrees to take on the role of Administering Practitioner and, at Claire's request, carries out the Assisted Death Care Plan meeting directly after granting approval.
- The Hospice is not registered as a place where assisted deaths may take place. Claire decides that she would like to return to the family home and for assisted death substance to be administered by the Administering Practitioner.
- The Administering Practitioner, who with Claire's permission has been liaising with Claire's husband, has already checked that Claire's home is a suitable place and with the help of the Care Navigator, has liaised with the Hospice regarding transferring Claire home.
- As discussed with the Coordinating Doctor and Independent Assessment
 Doctor during the assessment process, given the progression of her illness,
 Claire may soon lose decision-making capacity. Therefore, she decides to
 sign a Waiver of Final Confirmation of Consent, so that the Administering
 Practitioner may proceed with her wishes, in the event she loses capacity.
- The Administering Practitioner and MDT nurse attend the home the day after the approval decision was made. The Administering Practitioner carries out final review of Claire's capacity, request for an assisted death and that the decision is voluntary, settled and informed. Claire's condition has deteriorated significantly in the past 24 hours and the Administering Practitioner determines she no longer has decision-making capacity. As she has a Waiver of Final Confirmation of Consent in place, and shows no signs of refusal, the Administering Practitioner may proceed with the assisted death.
- The AP administers the assisted dying substance intravenously and Claire's death is recorded 6 minutes later. The Administering Practitioner completes the Post-Death Administration Form, this includes details of the substance administered, time of administration and time of death, any medical complications or interventions taken. It also notes Claire did not have decision-making capacity but did have a Waiver of Final Confirmation of Consent in place.
- Assisted death takes place 7 days after first formal request.

Summary of key safeguards

- Right of premises owner to refuse to assisted dying on premises
 - The Hospice maintained the right to object to Claire's death on their premises
- Locations for assisted death are pre-approved as suitable for an assisted death
 - Claire's home is visited by the Administering Practitioner, prior to approving it as suitable location for assisted dying in Assisted Death Care Plan
- Pace of process determined by individual and minimum timeframe may be waived if life expectancy is less than 14 days
 - Claire chose to move through process as quickly as possible as she was at the end stage of her disease, both assessing doctors were of the opinion that she had a life expectancy of less than 14 days and so was able to proceed to an assisted death before the full 14 day period of reflection, under Route 1.
- Waiver of Final Confirmation of Consent
 - O Claire was assessed and approved as eligible for assisted dying with decision-making capacity. Given the rapid deterioration of her condition, she made the decision to sign a Waiver of Final Confirmation of Consent. On the day, Claire was found to have lost decision-making capacity but the Administering Practitioner was able to proceed with the assisted death in accordance with Claire's wishes because of the Waiver was in place. If Claire had shown signs of refusal or distress, the Administering Practitioner would not have proceeded despite the Waiver being in place.
- Bereavement support for families
 - Although the family were supportive of her decision and considered this to be a positive choice, Claire's husband and young family were supported after her death.

- Sonia, 47 years old, no children
- Lives with her partner
- History of intervention from Social Services and States of Jersey Police, previously spent time in Women's Refuge
- History of depression, previous in-patient in mental health unit
- Recent diagnosis of melanoma (skin cancer)
- Due to have surgery to remove the melanoma in 1 week.

Possible safeguarding considerations

- Coercion from partner who has history of physical and emotional abuse.
- Decision-making capacity impaired by mental health.

- Sonia attends her GP with her partner in attendance, she makes a request for assisted dying. The GP does not conscientiously object to assisted dying but does not feel knowledgeable about the area. After a phone call to the Jersey Assisted Dying Service, and on the advice of the Care Navigator the GP refers Sonia to the Service.
- The Care Navigator calls Sonia later that day, her partner answers her mobile and reluctantly hands over the phone to Sonia. Sonia hesitantly makes an appointment.
- Sonia's partner accompanies her to that initial appoint with the Coordinating Doctor, at which Sonia makes her first formal request for an assisted death. She then requests a first assessment, and her partner also attends this. Her partner speaks on her behalf for much of the session.
- The Coordinating Doctor informs them that, as part of the assessment process, the Doctor needs to speak with Sonia alone. When the partner is out of the room, the Doctor asks further questions to examine the voluntariness of the Sonia's decision.

- The Coordinating Doctor has spoken with Sonia's surgical oncologist in advance and explains to her that the prognosis is good if she undergoes surgery. Sonia nevertheless continues to state that she wants an assisted death.
- The Coordinating Doctor raises their concerns about coercion with the MDT including the social worker who carries out an assessment, which includes speaking with other family members (Sonia has given her permission for these conversations to take place). The social worker is of the opinion that Sonia's decision cannot be confirmed as voluntary and free from coercion. Because of the doubts, the Coordinating Doctor determines she is not eligible for an assisted death.
- Sonia has a history of severe depression but during the assessment she does
 not exhibit signs of depression and because the Coordinating Doctor has
 already determined she is ineligible, a psychiatric assessment is not
 undertaken.
- The Coordinating Doctor meets with Sonia alone to explain the outcome of the assessment. The social worker is also in attendance.
- After much discussion she decides to undergo the surgery, she is also provided support by the Women's Refuge.

Summary of key safeguards:

- Eligibility criteria only allows for those who are making a voluntary, clear, settled and informed request
 - Sonia is assessed as ineligible, due to concerns about coercion by partner – her decision cannot be confirmed as voluntary.
- MDT and social worker assessment
 - Supports assessing doctor with consideration of non-medical aspects
 of assessment, specifically around suspected coercion and
 voluntariness of decision social worker carried out an additional
 assessment.
- Psychiatric assessment
 - Not used on this occasion as Sonia already ineligible, however due to history as in-patient in mental health unit, it is likely that assessing

doctor would have requested additional mental health assessment prior to making a determination.

- Signposting for additional support
 - o Sonia referred back into social services, due to vulnerable circumstances and supported by Women's Refuge.

- Annie, 29 years old, single
- Lives with parents
- Diagnosed with schizophrenia and severe depression aged 21

Possible safeguarding considerations

Decision-making capacity impaired by mental health

Circumstances / sequence of events

- Annie mentions her wish for assisted dying during a consultation with her psychiatrist at one of their regular appointments.
- The psychiatrist advises Annie of the assisted dying eligibility criteria (having undergone basic training on the assisted dying legislation) and explains that Annie is unlikely to be found eligible as her suffering is a result of mental illness, not a physical medical condition.
- The psychiatrist also informs Annie that they conscientiously object to assisted dying but provides her Annie with the contact details for the Jersey Assisted Dying Service.
- Annie calls the Service and speaks with a Care Navigator who advises the same, but Annie is adamant that she still wants to make a first formal request.
 The Care Navigator arranges for Annie to meet a Coordinating Doctor.
- At their meeting, the Coordinating Doctor spends time with Annie discussing the reasons for her request as well as explaining again that she would not be eligible.
- At the end of the meeting Annie decides not to make a First Formal request.
- The Coordinating Doctor and Care Navigator follow up with Annie's psychiatrist, with Annie's consent and an appointment is made with her psychiatrist to explore further care and treatment options.

Summary of key safeguards:

Option for self-referral

- The person has option to self-refer if health care professional conscientiously objects. The professional does, however, have a duty under their professional code of practice not to obstruct the person's wishes, so must inform them of the Jersey Assisted Dying Service.
- Right for health care professional to conscientiously object
 - Health care professional has right to conscientiously object and not participate in assisted dying, however as above, this does not extend to 'obstructing' the person from accessing a service which goes against the professional's personal beliefs.
- Eligibility criteria does not allow for those with unbearable suffering due to mental illness only
 - Annie may have been experiencing unbearable suffering, but under eligibility criteria set out in law, she would not be eligible as suffering must be a result of a *physical* medical condition.
- Signposting for additional support
 - Although Annie was ineligible, her suffering was significant, and as a result was referred back to her psychiatric consultant for additional support.

- Clive, 62, divorced, 2 adult children (estranged)
- Lives alone in a large property
- Sole beneficiary of large inheritance from recently deceased father
- Diagnosed with Motor Neurone Disease (MND) 12 months ago
- In receipt of palliative care

Possible safeguarding considerations

• Coercion from adult children who have been back in touch with father following death of grandfather. They are aware of the large inheritance.

- Clive was diagnosed with MND a year ago. His brother-in-law had
 previously died from the disease and Clive had witnessed his suffering.
 Hence Clive had been thinking a great deal about assisted dying but had not
 yet discussed the matter with anyone, including any health professionals.
- Clive's elderly father had recently died making him the sole beneficiary of a substantial inheritance. Clive had previously been estranged from his two adult sons, but those sons resumed contact on the death of Clive's father and quickly become fully immersed in Clive's life and care needs.
- Around a month after Clive's father's funeral, the sons raised the subject of
 assisted dying with Clive, explaining they think this would be best for him
 and offering to contact the Jersey Assisted Dying Service. Clive listens but
 does not share his own thoughts on assisted dying. He allows them to contact
 the Service on his behalf.
- Clive meets with the Coordinating Doctor to make a First Formal Request and decides to start the assessment process. He does this alone. He talks the Coordinating Doctor through his experience of his brother-in-law and how he's coping with his symptoms. He also talks through his relationship with his sons and their recent reappearance in his life.
- As part of the First Assessment process, a Social Worker carries out an assessment, meeting with Clive and his sons both separately and together.
 The social worker's assessment acknowledges the complex family

relationships and aspects of overly persuasive behaviour demonstrated by the sons. However, the social worker is confident that Clive's decision is voluntary and his wish for assisted dying pre-dates any involvement from his sons.

- The Coordinating Doctor requests an additional assessment from Clive's consultant. The outcome of this assessment is that Clive's life expectancy is no more than 12 months.
- As MND is a neurodegenerative condition which means the 12-month life expectancy timeframe applies - the Coordinating Doctor determines that Clive meets the eligibility criteria for assisted dying under 'Route 1 - terminal illness'.
- At Clive's request, an Independent Assessment Doctor then reviews the supporting assessment and opinions requested by the Coordinating Doctor, then carries out separate independent assessment. The Independent Assessment Doctor also determines that Clive is eligible under Route 1.
- Coordinating Doctor meets with Clive who makes a second formal request for assisted dying, signed by an independent witness.
- The Coordinating Doctor completes the Administrative Review, and approves Clive's request for assisted dying. Clive is informed that he may proceed to the planning stage for his assisted death when he chooses to (allowing for a minimum of two working days before the assisted death in the event of any appeal)
- An Administering Practitioner and Clive have an Assisted Death Care Plan meeting, at Clive's request, 1 week after he has been approved for assisted dying.
- Clive now uses a wheelchair and is exclusively fed via a feeding tube due to swallowing issues.
- The Administering Practitioner discusses Clive's options, he could still self-administer the assisted dying substance via his nasogastric tube (NG), or the practitioner could administer via NG or IV.
- Clive decides he want the assisted dying substance to be administered intravenously by the Administering Practitioner and that he wants to die at home, with his sons present.
- The Administering Practitioner and MDT nurse attend the home on the agreed time and date, 5 days after the Assisted Death Care Plan meeting.

- The Administering Practitioner carries out final review of Clive's capacity, request for an assisted death and that the decision is voluntary, clear, settled and informed.
- The Administering Practitioner administers the assisted dying substance intravenously and Clive's death is recorded 11 minutes later. The Administering Practitioner completes the Post-Death Administration Form, this includes details of the substance administered, time of administration and time of death.

Summary of key safeguards

- Eligibility criteria only allows for those who have a terminal neurodegenerative condition with a life expectancy of 12 months or less
 - Although Clive has significant physical challenges and suffers greatly from the impact of his condition, he can request assisted dying whilst he still has capacity to do so.
- Assessment process, not single appointment
 - Clive is able to discuss his wish for assisted dying at a number of sessions with both assessing doctors, this allows them to determine that Clive's request for assisted dying is *voluntary*, *clear*, *settled and informed*.
- MDT and social worker assessment
 - Additional social worker assessment considers family dynamic and rules out risk of coercion / non-voluntary request for assisted dying.

- Ricardo, 69, married, 1 child
- Lives with partner
- Paraplegic, following motorcycle accident 8 years ago
- Diagnosed with depression 4 years ago

Possible safeguarding considerations

• If decision-making capacity is impaired by mental health.

- Ricardo has discussed ending his life for many years following his accident.
 He has closely followed the development of assisted dying legislation in Jersey.
- As soon as the legislation comes into force, he contacts the Jersey Assisted Dying Service, with the support of his wife.
- The Coordinating Doctor meets with Ricardo and he makes his first formal request. During the session they discuss Ricardo's current prognosis, care and treatment as well as his request for assisted dying. He then signs the First Formal Request form.
- The Coordinating Doctor visits Ricardo at home again as part of first assessment process. During the assessment they spend more time discussing the care and treatment options Ricardo has already explored with his treatment team. They also discuss Ricardo's mental health, his previous episodes of depression and the less than ideal living conditions given the adaptations made to Ricardo's home for his power chair and hoists etc.
- Given Ricardo's mental health history, the Coordinating Doctor (with Ricardo's consent) requests an assessment by a Mental Health practitioner. The purpose of that assessment is to determine any possible new diagnosis of depression or anxiety, and also to confirm that, if Ricardo does have a diagnosed mental health condition, that it is not impacting on his decisionmaking capacity.
- The mental health assessment takes 4 weeks to arrange, as no on-island mental health practitioners will carry out assessments for the purposes of

- informing assisted dying eligibility decisions. A specialist from the UK is brought to the Island to carry out the assessment.
- The specialist concludes that Ricardo is suffering from mild depression, but that he retains decision-making capacity.
- An occupational therapist within the MDT carries out an assessment with Ricardo to determine if any further adaptations could be made to his home to alleviate his suffering. The assessment confirms that Ricardo's home is already well adapted, but the nature of his disability still makes daily activities very difficult and extremely painful.
- The Coordinating Doctor determines Ricardo to be eligible for assisted dying under 'Route 2 unbearable suffering'. During the discussion, Ricardo confirms that he wants support and treatment for his depression, but also wishes to proceed with his assisted dying request.
- At Ricardo's request, an Independent Assessment is arranged 10 days later, the Independent Assessment Doctor carries out separate independent assessment. Based on his in-person consultation with Ricardo, and the supporting assessment from the mental health specialist, the Independent Assessment Doctor also determines that Ricardo is eligible for assisted dying on the basis of his unbearable suffering due to a physical medical condition.
- Ricardo then makes his Second Formal Request, signed by an independent witness.
- The Coordinating Doctor, having undertaken an Administrative Review, provisionally approves Ricardo's request.
- As Ricardo is eligible under 'Route 2 unbearable suffering' the Coordinating Doctor's approval decision must be confirmed by the Assisted Dying Tribunal.
- The Care Navigator submits all relevant information to the Tribunal.
- The Tribunal considers the documentation and meets with Ricardo, his wife, the occupational therapist and the Coordinating Doctor. After 25 days the Tribunal confirms the Coordinating Doctor's decision to approve the assisted dying.
- It is now 93 days after Ricardo made his first formal request. Ricardo meets with the Administering Practitioner, and they develop his Assisted Death Assisted Death Care Plan:

- Ricardo decides he wants to self-administer the assisted dying substance
- o He wants to die at home with his wife and adult son present
- The Administering Practitioner and MDT nurse go to Ricardo's home on the agreed time and date, which is four days after the Assisted Death Care Plan meeting.
- The Administering Practitioner carries out final review of Ricardo's capacity, his request for an assisted death and confirms that his decision remains voluntary, clear, settled and informed.
- The Administering Practitioner supports Ricardo to self-administer the assisted dying substance. He enters a coma after 10 minutes and his death is declared 7 minutes later. The Administering Practitioner completes the Post-Death Administration Form, this includes details of the substance administered, time of administration and time of death.

Summary of key safeguards:

- 90-day minimum timeframe
 - As Ricardo's request falls under 'Route 2', there is a minimum of 90 days from first request to final review by the Administering Practitioner which allows for additional assessments, confirmation that the request is enduring, as well as time to ensure that all other options for the person have been explored in terms of treatment, pain relief and the provision of any other services that may be able to alleviate the person's suffering.
- MDT and Occupational Therapist and mental health assessment
 - The assessing doctors have an option to access additional opinion and assessments to support them to make determination of eligibility.
 These assessments included:
 - impact of living situation of 'unbearableness of suffering' –
 i.e. were any other care options or home adaptations available that might alleviate suffering
 - o impact of mental health on decision-making capacity
- Tribunal confirmation of approval
 - Allows for final confirmation of the Coordinating Doctor's approval, including further review of the more subjective aspects of the

determination, i.e., whether suffering is unbearable, voluntariness of decision etc.

- Otto, 91, widower, 2 children (both deceased), no close surviving relatives
- Lives in a residential care home
- No significant medical conditions, has type 2 diabetes and macular degeneration
- Feels disillusioned with life and has requested to die

Possible safeguarding considerations

No immediate family.

- Otto is an older man who lives alone in a Residential Home. Whilst he is friends with other residents, he has no surviving immediate family.
- At a regular GP appointment, Otto says he is 'tired of life' and is 'ready to go'. He mentions assisted dying and the GP makes a referral to the Jersey Assisted Dying Service.
- A Care Navigator contacts Otto and arranges an appointment at which Otto
 can make his first formal request. The Coordinating Doctor attends the
 residential home for the appointment. They discuss Otto's circumstances, his
 health and living circumstances. The Coordinating Doctor explains the
 assisted dying process, including the requirement for either a terminal
 diagnosis or unbearable suffering due to physical health condition.
- Otto and the Coordinating Doctor complete the First Formal Request Form and Otto indicates he wants a first assessment, which is arranged for the following week but postponed as Otto becomes unwell with pneumonia. Otto's condition worsens and he dies 3 days later.
- If Otto had had an assessment, he would have been found ineligible for assisted dying as he was 'tired of life' but at the time, did not have a terminal diagnosis nor was he experiencing unbearable suffering.
- In addition, the Residential Home had the right to refuse assisted dying on their premises. Whilst they permitted assessments on the premises, they did not permit assisted deaths. If Otto had been eligible for assisted dying, he

would have to have been transferred to Jersey General Hospital for the assisted dying to go ahead.

Summary of key safeguards:

- 'Tired of life' not an eligibility criteria
 - O Although Otto was not assessed for assisted dying, he would have been found to be ineligible on health grounds, given that at the time he had no terminal diagnosis, nor was experiencing 'unbearable suffering' due to a physical medical condition.
- Right of premises owner to conscientiously object to assisted dying on premises
 - Should Otto have been found eligible, the care home would have a right to refuse assisted dying on their premises, Otto would have been supported to be transferred to Jersey General Hospital (or another approved location) for his assisted death.

- Sadie, 31, single
- Lives with parents
- Diagnosed with anorexia aged 15, has been treated as an in-patient in specialist UK units on 3 occasions
- Diagnosis of end-stage heart failure as a result of her anorexia

Possible safeguarding considerations

May not have decision-making capacity.

- Sadie was diagnosed with anorexia as a teenager and has battled the disease for half her life. She also has end-stage heart failure as a result of her anorexia.
- During an appointment with her psychiatrist, Sadie expresses a wish for an
 assisted death. The psychiatrist explains that they object to assisted dying and
 will not discuss with Sadie, but they give her an information leaflet so Sadie
 can make direct contact with the Jersey Assisted Dying Service.
- The Coordinating Doctor meets with Sadie who makes a First Formal Request for assisted dying. During the appointment they discuss Sadie's medical history, including her heart failure which is likely to be terminal, and her wish for an assisted death.
- As part of assessment process, the Coordinating Doctor seeks advice from her cardiologist who confirms that Sadie's condition is terminal and there is a reasonable expectation she will die within 6 months.
- A specialist from the UK carries out a psychiatric assessment. At this stage it is determined that Sadie has decision-making capacity.
- At the end of the first assessment process the Coordinating Doctor determines that Sadie is eligible for assisted dying, under 'Route 1 - terminal illness' because of her heart failure.
- Sadie requests her second assessment two weeks later. The Independent Assessment Doctor reviews the first assessment, then carries out separate

assessment. The Independent Assessment Doctor meets Sadie in person and is concerned that Sadie's mental health condition has notably deteriorated. The Independent Assessment Doctor requests a second psychiatric assessment.

- At this appointment the specialist from the UK confirms that Sadie's mental health has deteriorated and is of the opinion that she no longer has decisionmaking capacity
- As a result of this, the Independent Assessment Doctor determines that Sadie
 is ineligible for assisted dying, as she does not have decision-making
 capacity.
- Sadie requests a second opinion; a Second Opinion Doctor is appointed who
 carries out a Second Opinion Independent Assessment. The Second Opinion
 Doctor reviews the previous assessments, meets with Sadie, the Coordinating
 Doctor and discusses the additional assessments with the UK psychiatrist.
 Based on their independent assessment of Sadie, the Second Opinion Doctor
 determines that Sadie is not eligible for assisted dying on the grounds that
 she does not have decision-making capacity.
- Sadie accepts the decision of the Second Opinion Doctor. Sadie dies two months later following a cardiac arrest.

Summary of key safeguards

- Eligibility criteria allows for assisted dying on basis of a terminal diagnosis of a physical medical condition, but not a mental illness
 - o Sadie may have been experiencing unbearable suffering as a result of her anorexia, but under eligibility criteria set out in law, she would not be eligible on these grounds as suffering must be a result of a *physical* medical condition.
 - O However, a secondary physical medical condition (i.e., heart failure) meant she could have been eligible for assisted dying.
- Eligibility criteria requires decision making capacity at each stage of the process
 - Whilst Sadie was assessed as having capacity during her first assessment, her mental health deteriorated and, when it was reassessed at the independent second assessment, she was found to no longer have decision-making capacity.

- Independent assessment by 2 doctors
 - Her medical diagnosis and decision-making capacity, was scrutinised by two doctors, as one of the doctors determined she did not meet the eligibility criteria, she was ineligible for assisted dying.
- Option for two psychiatric assessments, given her serious mental health condition and worsening of condition during the assessment process
 - O Additional assessments can be undertaken as part of the first assessment by the Coordinating Doctor, and as part of second assessment by the Independent Assessment Doctor. Given the change in circumstances it was appropriate for Sadie to have two separate psychiatric assessments to determine her eligibility.
- Right to Second Opinion
 - O Sadie was able to request a second opinion, following the Independent Assessment which found her to be ineligible. In this instance, the Second Opinion Doctor also determined her to be ineligible. But should they have found her to be eligible, following final administrative review by the Coordinating Doctor, she would likely have been approved for assisted dying.

Appendix 3: Forms and guidance

- 1. The law will require the Minister to bring forward the following forms and guidance:
 - a. Terms of Reference for the Assisted Dying Assurance and Delivery Committee by Ministerial Decision
 - b. **Right to Refuse and Conscientious Objection Guidance** setting out where professionals have the right to refuse direct participation in assisted dying
 - c. **Appropriate Conversations Guidance** Law will require Minister to bring forward non-statutory guidance to support all health and care professionals to speak with persons. Will include guidance for those who hold a conscientious objection
 - d. Training and qualifications requirements for registration as an assisted dying practitioner By Order of the Minister
 - e. **Step Transition form** By Order of the Minister
 - f. **Initial Enquiry form** By Order of the Minister
 - g. **First Formal Request form** By Order of the Minister
 - h. **First Assessment Report form-** By Order of the Minister
 - i. **Second Opinion Assessment Report form-** By order of the Minister
 - j. **Independent Assessment Report form** By Order of the Minister
 - k. **Assessing Doctor Transfer form** By Order of the Minister
 - 1. **Second Formal Request form** by Order of the Minister.
 - m. **Administrative Review (approve or decline) form** by Order of the Minister
 - n. **Assisted Dying Substance Dispensing form** by Order of the Minister
 - o. **Location Guidance** by Ministerial Decision which will set out that appropriate plans must be made, for example, if the assisted death is to take place in a care facility, there will need to be consideration of other individuals that may be present or close by during the assisted death

- p. **Final Consent and Review form** by Order of the Minister
- q. **Post-Assisted Death Administration form** Order of the Minister
- r. Assisted Dying Review Panel Terms of Reference adopted by Minister by Ministerial Decision, developed by the Assisted Dying Assurance and Delivery Committee:
- 2. The law will require the Assisted Dying Assurance and Delivery Committee to bring forward the following documents / guidance which must be developed in consultation with relevant stakeholders, for example the JCC and the UK professional regulators:
 - a. Assisted Dying Practitioner Competency Framework
 - b. **Support services package for assisted dying practitioners** access to psychological support
 - c. Services standards including target maximum timeframes for the Jersey Assisted Dying Service
 - d. Interpreting, Communication, Support and Advocacy Guidance
 - e. Guidance for Families and Carers
 - f. Assisted Dying Complaints and Concerns Policy
 - g. **Assessment Guidance** including first assessment, second assessment and second opinion assessments
 - h. Assisted Death Care Planning Guidance
 - i. Prescribing and Dispensing Guidance
 - j. Assisted Dying Substance Administration Guidance
 - k. Assisted Dying and Organ Donation Guidance
 - 1. **Training on Death Certification for Assisted Deaths** For ADRMP (assisted dying registered medical practitioner)

Appendix 4: Outline of mandatory training

Mandatory training: Assisted dying practitioners and Care Navigator

Assisted dying practitioners and Care Navigators will be required to undertake mandatory training, which is expected to take the form of a ten-day face-to-face modular programme. This will be followed by ongoing clinical supervision and case management. There will be a requirement for assisted dying practitioners to complete mandatory refresher training every three years.

The Committee will be required to develop the mandatory training programme. It is anticipated that the Committee would seek to collaborate with other jurisdictions, such as Australia and New Zealand, who already have established assisted dying practitioner training programmes.

Below is a summary of the envisaged key elements of the mandatory training

programme:

Provisional Assisted Dying Training Matrix - Face to Face Delivery						
DAY	TITLE	LEARNING				
1	Training Launch – Introductions and	What is Assisted Dying?				
	Understanding	• Who is eligible?				
		• Initial conversations with persons				
		 Role of professionals and MDT in assisted dying 				
		• Process of assisted dying, including person aftercare, reporting.				
		Right to refuse to participate				
		Codes of Conduct, professional regulation				
2	Legalities and Ethics	Advanced decision to refuse treatment and DNACPR (Do Not Attempt Cardiopulmonary Resuscitation) prior to assisted dying				
		Capacity and choice				

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		•	Duty of candour
		•	Consent and processes for assisted dying
		•	Comparison of Jersey assisted dying law to other jurisdictions – what can we learn?
		•	Safeguarding
		•	Policies and Procedures
3	Pause, reflect,	•	Support from teaching team and wellbeing team
	discuss and support	•	Time to pause and consider implications of role and moving forward with training
		•	Learner can withdraw at this point (in which case cannot become an assisted dying practitioner)
4	Drugs	•	Pharmacodynamics and pharmacokinetics
		•	Prescribing
		•	Dispensing
		•	Preparation
		•	Facilitation of Administration
		•	Interactions/Reactions/Unsuccessful Outcomes
5	Assisted dying in Practice	•	Case Studies
		•	Safeguarding
		•	Reporting Concerns
		•	Record Keeping
6	Death, dying and loss	•	Intensive Bereavement Training
	1055	•	Beliefs and Values – person and family

		•	Conflict resolution in the assisted dying environment
7	Simulation Day	•	Role Play and Simulation
		•	Clinical Skills e.g. cannulation, equipment, care after death
		•	Peer review and formative feedback
8	Personal and Professional Resilience	•	Wellbeing
		•	Counselling
		•	Self-Care
		•	Resilience and Coping Strategies
		•	Clinical supervision
9	Pause, reflect, discuss and support	•	Support from teaching team and wellbeing team
		•	Time to pause and consider implications of role and moving forward with role
		•	Learner can withdraw at this point (in which case cannot become an assisted dying practitioner)
10	Moving Forward	•	Monthly Clinical Supervision with designated supervisor
		•	Peer to peer support network
		•	MDT post case check in and review after every assisted dying

Note: the highlighted modules are built around reflection, wellbeing, personal values and the impacts of delivering an assisted dying service on the individual practitioner.

All health and care staff

Online and in-person training will be made available to all health and care staff on island, based on modules 1 & 2 of the Jersey Assisted Dying Service staff training. This training will cover:

- introduction to the legislation
- overview of the assisted dying process and the Jersey Assisted Dying Service
- discussing assisted dying with persons
- reference to relevant information and professional guidance including Appropriate Conversations Guidance (see from paragraph 105 of main report)
- referring persons to the services (see from paragraph 210 of main report)

Appendix 5: Timeline of activity

- **2018** e-petition signed by 1,861 people calling for the States Assembly to amend Jersey law and allow for assisted dying
- 2019 continued community interest in introduction of assisted dying in Jersey, including community-led public meetings and publication of survey on public and professional attitudes towards assisted dying, commissioned by End-of-Life Choices Jersey
- **February 2020** Health Minister commits to establishing a Citizens' Jury
- March September 2020 work delayed by covid pandemic
- March to May 2021 Jersey Assisted Dying Citizens' Jury takes place
- June 2021 Jersey Assisted Dying Citizens' Jury Initial Report published
- September 2021 Jersey Assisted Dying Citizens' Jury Final Report published
- **November 2021** the States Assembly agree, in principle, that assisted dying should be permitted in Jersey (P95/2021)
- March and April 2022 Phase 1 public engagement on assisted dying in Jersey
- May 2022 Publication of Phase 1 engagement summary report
- June 2022 Island-wide election new Council of Ministers formed
- October 2022 January 2023 Phase 2 consultation: assisted dying proposals
- April 2023 Publication of Phase 2 consultation feedback report
- July 2023 Minister for Health and Social Services commissions Ethical Review
- **November 2023** Publication of Ethical Review on Assisted Dying in Jersey
- January 2024 Vote of no confidence new Council of Ministers formed
- March 2024 Report and proposition on detailed proposals for assisted dying lodged for consideration by the States Assembly

Children's Rights Impact Assessment

A Children's Rights Impact Assessment (CRIA) has been prepared in relation to this proposition and is available to read on the States Assembly website.