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# STATES OF JERSEY



## REVIEW OF ASSISTED DYING (S.R.3/2024): RESPONSE OF THE MINISTER FOR HEALTH AND SOCIAL SERVICES

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Presented to the States on 17th May 2024  
by the Minister for Health and Social Services

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STATES GREFFE

REVIEW OF ASSISTED DYING (S.R.3/2024): RESPONSE OF THE  
MINISTER FOR HEALTH AND SOCIAL SERVICES

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<b>Ministerial Response to:</b>	S.R.3/2024
<b>Ministerial Response required by:</b>	21st May 2024
<b>Review title:</b>	Review of Assisted Dying
<b>Scrutiny Panel:</b>	Assisted Dying Review Panel

## INTRODUCTION

I thank the Assisted Dying Scrutiny Panel for its review of the assisted dying proposals (P18/2024). I note many of findings of the Panel and provides additional clarifying information where I have determined that additional information may be helpful to members of the public and States Members.

## FINDINGS

	<b>Findings</b>	<b>Comments</b>
1	There are three 'Success Criteria' within the Action Plan accompanying the Palliative and End of Life Care Strategy for Adults in Jersey, marked as 'Current / Ongoing' and three marked as 'Not Started'.	Correct. Work has now started on two of the three actions which were previously reported as having not started. This information will be set out in an updated strategy action plan to be published by end July 2024, once it has been considered and approved by the End-of-Life Strategy working group.
2	The evidence provided about the quality and the availability of the palliative and end of life care provision in Jersey, through long-term objectives and underpinning metrics within the Palliative and End of Life Care Strategy for Adults in Jersey, is key to providing States Members with necessary assurances prior to making their decision to support future assisted dying legislation.	Correct.
3	The inclusion of a 12-month life expectancy for Islanders with neurodegenerative conditions under Route 1: Terminal illness: <ul style="list-style-type: none"> <li>• Is a development beyond the original, in-principle, decision taken by the States Assembly in November 2021 to permit assisted dying.</li> </ul>	Correct.

	<b>Findings</b>	<b>Comments</b>
	Reflects the particular quality of life challenges faced by people with neurodegenerative conditions.	
4	It is unclear whether the concerns raised by the Ethical Review, particularly in relation to Route 2: Unbearable suffering, have been considered in detail prior to lodging the final proposals for debate by the States Assembly.	<p>On 25th April 2023, the Council of Ministers (COM) agreed to hold a series of Ministerial workshops to:</p> <ul style="list-style-type: none"> <li>• consider updates to assisted dying proposals in response to the consultation feedback,</li> <li>• confirm the content of draft proposals to be put forward for ethical review.</li> </ul> <p>At those workshops, attending Ministers, having considered the consultation feedback:</p> <ul style="list-style-type: none"> <li>• confirmed a number of amendments to assisted dying proposals (for example, the decision that the register of assisted dying professionals should be a private, as opposed to a public register; the inclusion of the 12-month life expectancy for people with neurodegenerative disease. Many of these changes are described in P18/2024, Appendix 1)</li> <li>• determined that both Route 1 and Route 2 should be retained as both Routes formed part of the P95/2021 in principle decision. Prior to making that determination the Ministers had considered the feedback on Route 2, and the associated divergence of views.</li> </ul> <p>COM ratified this decision at its meeting on 11 July 2023 and determined that the proposals to be examined by the Ethical Review should include both Route 1 and Route 2.</p> <p>The Ethical Review report was subsequently published on 7 November 2023. The Route 2 concerns raised by the Ethical Review authors were subsequently considered by Ministers. (Note: The Ethical Review Panel directly provided briefing meetings for the Council of Ministers; Scrutiny; States Members).</p> <p>Further to those briefings, and having further considered the findings of the Ethical Review in discussion with Officers, the previous Ministers for Health and Social Services, Justice and Home Affairs, and the Environment determined that:</p> <ul style="list-style-type: none"> <li>• Route 2 should be retained in the proposals presented to the Assembly (ie. should form part of P18/2024) on the basis that Route 2 was a central feature of the Citizen’s Jury</li> </ul>

	Findings	Comments
		<p>and the Assembly's P95/2021 decision making</p> <ul style="list-style-type: none"> <li>Officers should undertake additional engagement work with people disabilities / long-term conditions on assisted dying post publication of the P18/2024 proposals. (The feedback from this engagement is set out in an addendum to P18/2024)</li> </ul> <p>Note: The previous Chief Minister determined that that previous Ministers for Health and Social Services, Justice and Home Affairs, and the Environment should form an Assisted Dying Ministerial Group and, on behalf of COM, finalise any outstanding matters.</p> <p>Post the change of Government, I determined that I would uphold the decisions of the previous Ministers, including retaining Route 2 in the P18/2024 proposals, which were subsequently approved for lodging by COM on 5 March 2024.</p>
5	<p>Details about the level of concern amongst respondents about the inclusion of Route 2: Unbearable suffering, as a percentage breakdown of the 1,300 respondents to the Phase 2 Consultation Feedback Report, were not provided.</p>	<p>This information would have been provided if it were available. As explained to the Panel (<a href="#">letter dated 10 April 2024</a>) and set out in P18/2024 Appendix 1, paragraph 3 the Phase 2 consultation survey did not ask a specific question on whether Route 2 should be permitted, as the States Assembly had already decided 'in principle' that it should and, as such, it is not possible to provide a percentage breakdown of respondents who support / do not support Route 2.</p>
6	<p>On the advice of the Children's Commissioner, children were not consulted on the final proposals due to the distressing nature of assisted dying, however, the provision of assisted dying for Islanders with mental illness and those under the age of 18 may be subject to future consideration.</p>	<p>P18/2024 does not suggest that future assisted dying provision may be made for children and / or Islanders with mental illness. It accepted, however, that any future Assembly may choose to amended the eligibility criteria, whether or not to include children and / or people with a mental illness.</p> <p>As per P18/2024 page 173:</p> <p><i>“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</i></p>

	<b>Findings</b>	<b>Comments</b>
		<p><i>'slippery slope' of expanding eligibility criteria, particularly with regard to potential expansion to allow assisted dying for those aged under 18</i></p> <div style="border: 1px solid black; padding: 5px;"> <p><b>Regulation make power: Summary of key changes / clarifications</b></p> <p><i>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”</i></p> </div>
7	Any future proposed changes to the assisted dying eligibility criteria will first require approval by the States Assembly.	Correct
8	The European Convention on Human Rights, which extends to Jersey and is incorporated into domestic Law by the Human Rights (Jersey) Law 2000, does not provide a person with the right to die.	Correct
9	The final proposals for assisted dying do not specify the training requirements in relation to the identification and prevention of coercion.	Correct. As explained to the Panel ( <a href="#">letter dated 10 April 2024</a> ) reference to training requirements related to identification and prevention of coercion was omitted from the P18/2024 proposals. This was an accidental omission and training will include matters relating to coercion.
10	The requirements of members of the assisted dying tribunals will be determined by The Tribunal Service.	Correct
11	The presumption of decision-making capacity within the final proposals is in line with the general law governing capacity, however, it is unclear whether the removal of the presumption of decision-making capacity was considered as part of the development of the final proposals, as recommended by the Ethical Review.	<p>The matters raised by the Ethical Review, including the removal of the presumption of capacity, were considered by Ministers. This included:</p> <ul style="list-style-type: none"> <li>• the Ethical Review Panel directly provided briefing meetings for the Council of Ministers (COM); Scrutiny; States Members, and;</li> <li>• detailed consideration by the Assisted Dying Ministerial Group (which included the previous Ministers for Health and Social Services, Justice and Home Affairs, and Environment).</li> </ul>

	Findings	Comments
		<p>On 24 October 2023, the Assisted Dying Ministerial Group attended the COM pre-publication briefing on the findings of the Ethical Review by the authors. In response to that briefing and a further meeting with officers on 26 October 2023, the Ministers instructed officers to give further examination to the matters related to the potential removal of the presumption of decision-making capacity. In response to this instruction Officers sought further advice from the Law Officers Department (LoD) and from the Government of Jersey professional leads on capacity and self-determination (there had been previous discussions with LoD and the professionals leads as part of the process of developing the initial proposals).</p> <p>On the back of the additional advice received, Officers proposed that the presumption of capacity should be retained as it was already established as important principle in Jersey law, and other jurisdictions that set out a specific capacity test for an assisted dying decision in law, had also retained a presumption of capacity.</p> <p>The previous Minister for Health and Social Services, having considered that additional advice received, subsequently advised in the Assisted Dying Ministerial Group that it should be retained.</p>
12	Assisted dying capacity training will focus on how professionals undertake capacity assessments and make determinations that relate to the specific capacity test for assisted dying.	Correct.
13	The capacity test for assisted dying will be more extensive than that required under the Capacity and Self Determination (Jersey) Law 2016, however, it is unclear what the specific capacity test for assisted dying will be and what the additional requirements will be.	<p>P18/2024 proposes that law will set out a specific assisted dying capacity test and, as per paragraph 289, it is proposed a person will have decision-making capacity in relation to assisted dying if they have the capacity to:</p> <ol style="list-style-type: none"> <li data-bbox="794 1615 1289 1742">a. <i>“understand any information or advice about an assisted dying decision that is required under the law to be provided to them</i></li> <li data-bbox="794 1783 1289 1845">b. <i>understand the matters involved in an assisted dying decision</i></li> </ol>

	<b>Findings</b>	<b>Comments</b>
		<p><i>c. understand the effect of an assisted dying decision</i></p> <p><i>d. weigh up the factors referred to above for the purposes of making an assisted dying decision</i></p> <p><i>e. communicate an assisted dying decision in some way (including verbally, using gestures or by other means)."</i></p> <p>The exact test and any associated additional requirements will be clarified during the law drafting phase.</p>
14	The Administering Practitioner will be trained to recognise verbal and non-verbal cues associated with refusal or resistance to an assisted death.	Correct.
15	Some respondents with a healthcare background that responded to the Phase 2 Consultation on Assisted Dying believed at least five years' or 10 years' experience is required for doctors and registered nurses assigned to the Administering Practitioner role.	<p>Correct.</p> <p>P18/2024 currently provides that, to be an assisted dying practitioner, professionals need to be 12 months post professional registration. 12 months accords with advice from the GMC.</p> <p>I am, however, aware that some on-island health and care practitioners have expressed ongoing concern about this time period (contrary to the position of their professional registration bodies who have not raised any concerns) and will undertake further consultation on this matter during the law drafting phase.</p>
16	Further work to clarify the types of premises where a right to refuse to participate could apply will be undertaken as part of the development of assisted dying legislative drafting instructions.	Correct.
17	Discussions are underway about appropriate places within the Jersey General Hospital for assisted dying.	Correct. It has been discussed and agreed that assisted deaths should not be permitted on a general ward and that, post Assembly decision making on 21 May 2024, further consideration should be given to an appropriate place.
18	The final proposals for assisted dying require appropriate planning for other patients and residents in Government of	Correct.

	<b>Findings</b>	<b>Comments</b>
	Jersey owned and / or managed care facilities.	
19	The assisted dying legislation will remain silent regarding discussions about assisted dying between healthcare professionals and patients, however, the Minister for Health and Social Services will bring forward 'Appropriate Conversations Guidance' to clarify the circumstances where raising the issue of assisted dying may be appropriate.	Correct. This position is supported by the General Medical Council (GMC) and Nursing and Midwifery Council (NMC).
20	The Panel's Amendment to the final proposals is intended to give more clarity and flexibility when interpreting the word "participation" in assisted dying.	Noted.
21	The publication of an Assisted Dying Annual Report is intended to balance the need for transparency and destigmatisation of assisted dying against respect for patient privacy.	Correct.
22	The work to develop the assisted dying training programme and guidance will commence following the States Assembly debate on the final proposals on 21st May 2024.	Correct.
23	It is unclear what items of guidance will be developed and prioritised for consideration prior to the States Assembly debate on assisted dying legislation.	Correct. As explained to the Panel ( <a href="#">letter dated 10 April 2024</a> ) a detailed summary of the content of the training programme and guidance will be provided to the Assembly alongside the draft law. It is not possible to provide details of items of guidance at this stage.  As the Assembly has not yet determined key elements of the proposed law, officers are unable to provide a full list of items of guidance to be developed.
24	The details about all of the guidance to be produced will be finalised during Quarter 1 and Quarter 2 of 2026, after the States Assembly has made a decision on the draft assisted dying legislation.	Correct. The guidance flows from the law, so it cannot be finalised until any law has been adopted.
25	The draft assisted dying law will be published with an accompanying detailed summary of the assisted dying training programme.	Correct.



	<b>Findings</b>	<b>Comments</b>
26	The Minister for Health and Social Services would be required to suspend the provision of assisted dying in Jersey, in the event that adequate funding was not available or adequate staffing was not available for the service to be delivered safely and in accordance with law.	Correct.
27	The Panel is unclear about how broader staffing and recruitment challenges will be addressed in relation to the additional resource implications associated with the provision of assisted dying in Jersey.	This matter cannot be more adequately addressed until the Assembly has determined the scope of any draft law, and further survey work is undertaken amongst health and care professionals about their willingness to participate in an assisted dying service. See P18/2024: Note to Staffing, between paragraphs 136 and 137.
28	The potential risks associated with suspension of assisted dying in Jersey will be described in a full risk assessment of the assisted dying provisions and presented to the States Assembly alongside the draft assisted dying law.	Correct.

**Key Recommendations:**

	<b>Recommendations</b>	<b>To</b>	<b>Accept/Reject</b>	<b>Comments</b>	<b>Target date of action/ completion</b>
1	<b>Key Recommendation 1:</b> The Minister for Health and Social Services should publish a plan to evidence the quality and availability of palliative and end of life care in Jersey, by no later than two months before the assisted dying legislation is scheduled for debate by the States Assembly.	MHSS	Accept	Evidence related to the quality and availability of palliative and end of life care in Jersey will be made available.	Two months before scheduled debate on draft law.
2	<b>Key Recommendation 2:</b> The Minister for Health and Social Services should publish an appendix to the final proposals for assisted dying, setting out the training requirements, that comprehensively cover the identification of and	MHSS	Accept	It is envisaged that there will be an extended lodging period for the draft assisted dying law (in the event that the Assembly agree to proceeding to	Two months before scheduled debate on draft law.

	prevention of coercion by no later than two months before the assisted dying legislation is scheduled for debate by the States Assembly.			law drafting). The draft law would be accompanied by supporting information that will include detail of the training and guidance requirements, which would include matters related to identification and prevention of coercion.	
3	<b>Key Recommendation 3:</b> The Minister for Health and Social Services must ensure sufficient planning is in place to prioritise patient wishes about possible locations for assisted dying, including within the home, and that the Jersey General Hospital is only used for assisted dying as a last resort.	MHSS	Accept	-	To be undertaken during implementation phase (2026 to early 2027)
4	<b>Key Recommendation 4:</b> The Minister for Health and Social Services should support the Panel's Amendment to the final proposals for assisted dying.	MHSS	Accept	COM comment accepting amendment was lodged on 14 May.	Complete

### RECOMMENDATIONS

	Recommendations	To	Accept/Reject	Comments	Target date of action/completion
1	The Minister for Health and Social Services should publish information about the	MHSS	Accept in part	An action plan will be published by end July 2024. It cannot be published by 21 May as it needs to be considered and	By end July 2024

	<b>Recommendations</b>	<b>To</b>	<b>Accept/ Reject</b>	<b>Comments</b>	<b>Target date of action/ completi on</b>
	progress of the actions marked as 'Current / Ongoing' and 'Not Started' within the Action Plan accompanying the Palliative and End of Life Care Strategy for Adults in Jersey, by no later than Tuesday 21st May 2024.			approved by the End of Life Strategy working group.	
2	The Minister for Health and Social Services should confirm the timeline for the development of a Palliative and End of Life Care Strategy beyond 2026, by no later than two months before the assisted dying legislation is scheduled for debate by the States Assembly.	MH SS	Accept	-	Two months before scheduled debate on draft law.
3	The Minister for Health and Social Services should publish details about how the concerns raised by the Ethical Review in relation to Route 2: Unbearable suffering, were considered as part of the development of the final proposals for assisted dying, by no later than Tuesday 21st May 2024.	MH SS	Accept	Completed. See response to Finding 4 above which contains the information requested in this recommendation.	
4	The Minister for Health and Social Services should not undertake any consultation with children on assisted dying without engaging first with the Children's Commissioner.	MH SS	Accept	To date, there has been no direct consultation with children because it would have been contrary to advice from the Children's Commissioner. If I were to be considering any future consultation with children, I would first seek advice and input from the Children's Commissioner.	As and when required

	<b>Recommendations</b>	<b>To</b>	<b>Accept/ Reject</b>	<b>Comments</b>	<b>Target date of action/ completi on</b>
5	The Minister for Health and Social Services should publish details of any previous or ongoing consultation with the Tribunal Service about the required skillset of Assisted Dying Tribunal Members, by no later than Tuesday 21st May 2024.	MH SS	Accept	<p>P18/2024 proposes that the Tribunal will consist of one legal member, one medical member and one lay member. The Judicial Greffier was sighted on that proposal ahead of publication.</p> <p>The Panel were informed, at the Assisted Dying Review Panel meeting on 3 April that:</p> <ul style="list-style-type: none"> <li>• there had been active and live discussions about the skillset required by Tribunal members (ie. discussions amongst officers researching comparable skills requirements in order to frame the P18/2024 proposals for discussion with the Judicial Greffier prior to publication of the proposals)</li> <li>• the determination of the skills set / level of experience required would be a matter for the tribunal service, and that it was anticipated that tribunal service will develop the requirements the point at which the Tribunal Service is looking to stand up a tribunal.</li> </ul> <p>Further to the publication of the proposals there has been no ongoing consultation with the Tribunal Service, as there is not information to provide.</p>	Completed.  See information set out in the Comments column which provides the information requested.
6	The Minister for Health and Social Services should publish the full details and processes for establishing refusal or resistance to an assisted death for a person who	MH SS	Accept	-	Two months before scheduled debate on draft law.

	<b>Recommendations</b>	<b>To</b>	<b>Accept/ Reject</b>	<b>Comments</b>	<b>Target date of action/ completi on</b>
	has lost decision-making capacity, by no later than two months before the assisted dying legislation is scheduled for debate by the States Assembly.				
7	The Minister for Health and Social Services must provide details about the timeline and stakeholders involved in discussions regarding appropriate places within the Jersey General Hospital for assisted dying, by no later than two months before the assisted dying legislation is scheduled for debate by the States Assembly.	MH SS	Accept	-	Two months before scheduled debate on draft law.
8	The Panel is keen to ensure that assisted dying is only carried out within the Jersey General Hospital as a last resort, and the Minister for Health and Social Services must ensure that the Jersey Assisted Dying Service is not headquartered within the Jersey General Hospital.	MH SS	Accept in part	I agree that an assisted death should only be carried in the Jersey General Hospital as a last resort, taking into consideration the wishes of the patient.  At this point in time, no detailed consideration has been given to the location of the headquarters of the Jersey Assisted Dying Service (which is delivering administrative tasks / coordinating assessment processes), hence I believe it is pre-emptive to commit not to headquarter in the Hospital. In making this decision I will, in consultation with key stakeholders, need to weigh up the impact on people who want to access the Assisted Dying Service and the impact on other users of hospital services.	N/A
9	The Minister for Health and Social Services must ensure robust planning is in place to mitigate the potential impact of	MH SS	Accept	-	Two months before scheduled debate

	<b>Recommendations</b>	<b>To</b>	<b>Accept/ Reject</b>	<b>Comments</b>	<b>Target date of action/ completion</b>
	assisted dying on any other residents or patients of Government of Jersey owned and / or managed care and nursing facilities, by no later than two months before the assisted dying legislation is scheduled for debate by the States Assembly.				on draft law.
10	<p>The Minister for Health and Social Services should publish details and plans about assisted dying training and guidance that include:</p> <ul style="list-style-type: none"> <li>• A detailed summary outlining all items of assisted dying guidance to be developed and produced.</li> <li>• The items of guidance to be prioritised, shared and presented to States Members.</li> <li>• Details and plans about the development of the assisted dying training programme.</li> </ul> <p>This information should be provided no later than two months before the assisted dying legislation</p>	MH SS	Accept	See response to Key Recommendation 2 above.	Two months before scheduled debate on draft law.

	<b>Recommendations</b>	<b>To</b>	<b>Accept/ Reject</b>	<b>Comments</b>	<b>Target date of action/ completi on</b>
	is scheduled for debate by the States Assembly.				
11	The Minister for Health and Social Services should provide details about how general recruitment and staffing challenges across the Health and Community Services Department will be addressed in relation to the additional resource implications associated with the Jersey Assisted Dying Service, by no later than two months before the assisted dying legislation is scheduled for debate by the States Assembly.	MH SS	Accept	-	Two months before scheduled debate on draft law.
12	The Minister for Health and Social Services should provide details and plans to mitigate and respond to the risk of Health and Community Services not being able to recruit sufficient staff to the Jersey Assisted Dying Service, by no later than two months before the assisted dying legislation is scheduled for debate by the States Assembly.	MH SS	Accept	-	Two months before scheduled debate on draft law.

### **CONCLUSION**

I accept the recommendations of the Panel, except for where I consider that it would be pre-emptive to do so until further consideration has been given to the matter (noting that, once further consideration has been given to the matter, I may adopt the recommendation).