

Assisted Dying in Jersey

Summary of Proposals

OCTOBER 2022



Assisted dying in Jersey: summary of full proposals

In November 2021 Jersey's States Assembly became the first parliament in the British Isles to decide 'in principle' that assisted dying should be allowed. They also decided that plans should be made for an assisted dying service.

This document provides a summary of the assisted dying proposals. The full proposals are set out in the consultation document, which is accompanied by a survey. These can be found at www.gov.je/assisteddying.

During March and April 2022 Islanders were asked to take part in the <u>first phase of public engagement</u> on assisted dying.

This second phase of consultation will run from **17 October 2022** to **14 January 2023**. It is an opportunity for you to share your views and help shape proposals for assisted dying in Jersey.

What is 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 medical professional.

Assisted dying is not the same as suicide. Assisted dying is a service provided to people in certain limited circumstances that will be set out in law.

It 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.

Summary of assisted dying proposals

This document is a summary of the detailed assisted dying proposals. It is divided into five sections:

- 1. Eligibility criteria
- 2. Jersey Assisted Dying Service
- 3. Assisted dying process
- 4. Regulation and oversight
- 5. Responding to the consultation and next steps



Section 1. Eligibility criteria

This section describes the proposed eligibility criteria for accessing an assisted death. A person must meet **all** the eligibility criteria. They must:

- a. have an eligible condition
- b. have decision-making capacity
- c. have a voluntary, settled and informed wish for an assisted death
- d. be at least 18 years of age
- e. fulfil residency requirements.

a. Have an eligible condition

- Those eligible must have been diagnosed with:
 - 1) a terminal physical medical condition, known as 'Route 1 terminal illness'; OR
 - 2) an incurable physical condition, causing unbearable suffering, known as 'Route 2 unbearable suffering'.
- To be eligible under 'Route 1 terminal illness', the person must have been diagnosed with a terminal physical medical condition that is expected to:
 - cause death within 6 months (Or within 12 months if diagnosed with a neurodegenerative condition such as Parkinson's disease or Motor Neurone Disease)
 - cause unbearable suffering.s
- To be eligible under 'Route 2 (unbearable suffering)', the person must have been diagnosed with an incurable physical medical condition that is causing unbearable suffering that cannot be alleviated in a manner the person deems tolerable.

b. Have decision-making capacity

- A person has decision-making capacity for assisted dying if they can:
 - understand any information or advice given to them about an assisted dying decision
 - 2. understand the matters involved in an assisted dying decision
 - 3. understand the effect of an assisted dying decision
 - 4. weigh up the factors for the purposes of making an assisted dying decision
 - 5. communicate an assisted dying decision in some way (including verbally, using gestures or by other means).
- A person is presumed to have decision-making capacity for assisted dying unless there is evidence to the contrary.



c. Have a voluntary, settled and informed wish for an assisted death

- A person must want an assisted death. They must be acting without coercion, or persuasion by another person, which may be a family member.
- The assisted dying process has built in controls to ensure the person's wish is settled.
 The person must articulate their wishes throughout the process, and each step of the
 process can only be initiated by the person expressing a wish to proceed to the next
 step.
- The law requires that the person requesting the assisted death must be fully informed about:
 - 1. their diagnosis, prognosis and all available care and treatment options
 - 2. all aspects of the assisted dying process.

d. Be at least 18 years of age

• Assisted dying will only be available to people aged 18 years or older.

e. Meet residency requirements

- To be able to access assisted dying a person must have been ordinarily resident in Jersey for at least 12 months prior to making their first formal request for an assisted death.
- '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 are on holiday in Jersey.

Section 2. Jersey Assisted Dying Service

This section explains how an assisted dying service would be provided in Jersey. It gives detail on:

- a. Jersey Assisted Dying Service
- b. professionals providing the Assisted dying service
- c. conscientious objection

a. Jersey Assisted Dying Service

• The Jersey Assisted Dying Service will be delivered by the Health and Community Services Department (HCS).



- The Jersey Assisted Dying Service will:
 - provide a point of contact for anyone who wants information about assisted dying or is considering requesting an assisted death
 - o support people to navigate the assisted dying process
 - o support the loved ones of people who have requested an assisted death
 - o coordinate and deploy the professionals engaged in the assisted dying process.
- The assisted dying service will be available free of charge to any person who meets all eligibility criteria (see section 1).
- A Delivery and Assurance Board will oversee the clinical and corporate governance of the Jersey Assisted Dying Service, which means ensuring that:
 - o the assisted dying service is safe
 - o standards of care are high
 - o the service is well run, and patient centred
 - there is fair access to the service.
- The Delivery and Assurance Board will also be responsible for commissioning an administrative review of each assisted death.

b. Professionals providing the Assisted dying service

- Health professionals can choose to work in the assisted dying service. To be an assisted dying practitioner, they must:
 - be registered with the Jersey Care Commission to work in Jersey
 - have completed assisted dying training
 - be able to demonstrate they meet the requirements set out in the competencies framework (the competencies framework is a document which is approved by the Delivery and Assurance Boards which specifies the knowledge, skills, and attributes required for each assisted dying role)
 - make a decision to 'opt-in' to work as assisted dying practitioner with the Jersey Assisted Dying Service.
- The specific roles in the assisted dying process are:
 - 1. **Care navigators** non-clinical staff who will support the person requesting an assisted death, as well as providing support and information to the general public and health & care staff



- 2. **Coordinating Doctor** the doctor who undertakes the first assessment of the person who has requested an assisted death, and coordinates the assessment process
- 3. **Independent Assessment Doctor** the doctor who undertakes the second assessment of the person who has requested an assisted death.
- 4. **Pharmacy professionals** pharmacists and pharmacy technicians who will prepare and dispense the substance used in assisted dying
- 5. **Administering doctor or nurse** who will directly administer the substance used in assisted dying or support the person to self-administer.
- Professionals participating in assisted dying will have access to support services, for example psychological support.

c. Conscientious objection

- A right to conscientious objection ensures that people are free to act in accordance with their own personal beliefs about assisted dying.
- The assisted dying law will state that no-one can be compelled to *directly* participate in the assessment, approval or delivery of an assisted death.
- However, there may be certain elements of a person's job that may relate *indirectly* to assisted dying. A right not to participate in these indirect tasks would not be covered by a conscientious objection clause.
- There are also some tasks where it may not be clear whether they relate direct or indirectly
 to assisted dying. The survey which accompanies the full consultation document asks
 questions about which tasks should be included in the scope of conscientious objection
 clause.
- The table below highlights some examples of tasks that relate directly and indirectly to assisted dying:



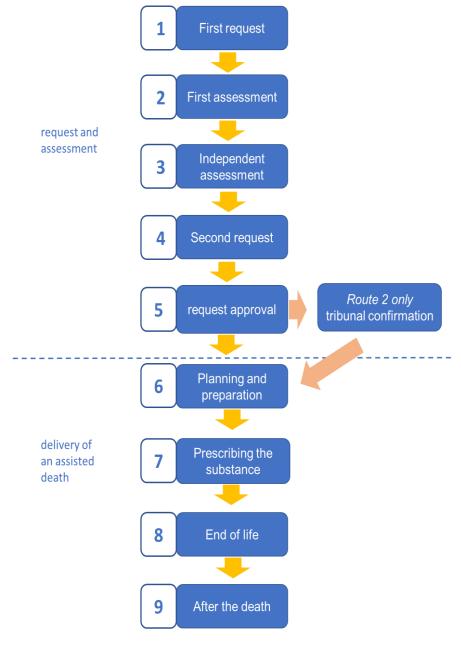
Tasks relating indirectly to assisted dying	Tasks relating directly to assisted dying	Tasks that may be considered as direct participation
Will not be covered by conscientious objection	<u>Will be</u> covered by conscientious objection	<u>May be</u> covered by conscientious objection – subject to consultation
Providing usual care or treatment to a person who has requested assisted dying (e.g., looking after a person in their residential home)	Supporting a person to access an assisted death	Providing a supporting opinion to the Coordinating Doctor to help them determine if a person is eligible for an assisted death (e.g. opinion on life expectancy or ancillary tests such as pulmonary function tests)
Administrative tasks (e.g., undertaking a residency check)	Undertaking any of the specified roles (e.g., 'Coordinating doctor')	Giving permission for a person to have an assisted death on your premises (for example, in a care home or hospice)
Delivery of equipment or medical supplies for use in assisted dying	Directly supporting the administration of an assisted dying substance	

- For tasks that are within the scope of conscientious objection specific guidance will be published. Health professionals must still act in accordance with the guidance of their professional registration body. In refusing to participate they must not, for example:
 - o treat patients who wants an assisted death unfairly
 - o deny patients access to appropriate medical treatment or services
 - o cause distress to the patient.



Section 3. Assisted dying process

- There are 9 steps in the assisted dying process. The first 5 steps relate to the request, assessment and approval for an assisted death. Steps 6 to 9 relate the delivery of an assisted death.
- The person requesting an assisted death is in control of the process and must express a wish to proceed to each step at their own pace. They can stop the process at any time.



Flow chart outlining the steps in the assisted dying process



- The minimum time for which steps 1 to 8 can be completed for those following 'Route 1' (terminal illness) is 14 days. The 14-day period ensures that the person who has requested an assisted death has time to reflect on their decision, but it is not an excessively long time period for those close to the end of their life.
- The minimum time for which steps 1 to 8 can be completed for those (unbearable suffering) it is 90 days. This longer time period acknowledges the significance of the person, who does not have a terminal diagnosis, potentially shortening their life by years.
- The 90-day period allows time for additional assessments and opinions to be sought, and
 confirmation that the person's wish is settled. It also allows for the assessing doctors and
 the person to be satisfied that all options have been explored in terms of treatment, pain
 relief and the provision of any other services that may alleviate the person's suffering.

Step 1. First request

- Before making a formal first request, a person may raise the issue of assisted dying directly with the Jersey Assisted Dying Service, or with someone else is providing them with care or treatment, for example, their GP.
- The Jersey Assisted Dying Service will provide accessible information for people considering an assisted death, their friends, family members and health professionals.
- Guidance will be published, and training made available for all health and care
 professionals to support them to manage conversations about assisted dying if someone
 raises the issue with them.
- Once a person has considered the matter, they may choose to make a formal request.
 This initiates the assisted dying process.
- The first formal request must be made by the person to the Coordinating Doctor. The request must be:
 - clear and unambiguous, so the Coordinating Doctor knows exactly what the person is asking
 - o made by the person and not by another person on their behalf
 - o written, or made verbally or by other means of communication such as gestures.

Step 2. First assessment

- The Coordinating Doctor will assess if the person is <u>eligible for assisted dying</u> and meets the criteria in law (see section 1). The first assessment may take a few hours or happen over several days.
- The first assessment is an opportunity for the person to fully explore with the doctor:
 - their request for an assisted death and the fears, anxieties and suffering that gives rise to that request



- other care / treatment options and other ways to alleviate their fears and anxieties (for example, they may have financial concerns or concerns about being a burden on family carers)
- The Coordinating Doctor may ask other health professionals for their professional opinion as part of the assessment process. They may also request additional assessments to help them determine whether the person meets the criteria, for example, a capacity assessment.
- If the person is assessed as not meeting the criteria by the Coordinating Doctor, the process will stop unless the person seeks a second opinion assessment.
- A second opinion assessment follows the same process as the first assessment. If the second opinion assessment determines the person is eligible, the person may choose to proceed to the second assessment (independent assessment).
- If the Coordinating Doctor (or the doctor carrying out the second opinion assessment) determines the person is ineligible, they will talk to them about care and support services that may help them.

Step 3. Independent assessment

- An Independent Assessment Doctor will do a second assessment to decide if the person is eligible.
- They must also independently assess the person against the <u>eligibility criteria</u> set out in law (see section 1) and form their own opinion.
- The Coordinating and Independent Assessment Doctor must both assess the person as eligible before the person can make a second request.

Step 4. Second request

- If the person still wishes for an assisted death, they must make a second formal request. This will take the form of a written declaration.
- The person must make the written request in the presence of a witness and an involved professional who must sign and date the request.



Waiver of final consent

If a person is eligible under Route 1 (terminal illness), they may choose to make a waiver of final consent. A waiver of final consent 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 give their final consent (Step 8), the assisted death can still take place.

If the person makes a waiver of final consent they will need to agree their wishes for their assisted death with the Coordinating Doctor. This would include, for example, the date and location

Step 5. Request approval

- For both Route 1 (terminal illness) and Route 2 (unbearable suffering) the Coordinating Doctor will approve the assisted dying request but can only do so if both the Coordinating Doctor and the Independent Assessment Doctor have determined that the person meets all the criteria.
- For Route 2 (unbearable suffering), an additional step of Tribunal approval is required. There is no expiry for an approval for an assisted death.

Approval for Route 1 (terminal illness)

• The Coordinating Doctor undertakes a review to confirm the request and assessment process has been completed correctly.

Once the Coordinating Doctor has completed the request approval form, the person can decide to move on to the next stage of the process – Step 6 Planning and Preparation.

• There must be at least 48 hours between when the request approval form is signed (Step 5) and the final review (step 8), to allow for appeals (see below 'Appeals').

Approval for Route 2 (unbearable suffering)

- Once the Coordinating Doctor has completed the request approval form, a special Tribunal will review decisions made by Coordinating Doctors to approve Route 2 assisted dying requests. The Tribunal may either confirm or reject the Coordinating Doctor's approval of the request.
- The Tribunal will review all relevant information from the assessment process. They may
 decide to request further assessments of the person or request information or evidence
 from the person, their friends and family or other professionals involved in their treatment
 and care.



- Each Tribunal panel will consist of a legal member, a medical member and a lay member.
- Tribunal must review the approval for an assisted death within 30 days.

Appeals

- An appeal can be made to the Royal Court in relation to an assisted dying decision.
- An appeal can be made to the Royal Court by:
 - the person who has requested an assisted death (or someone they have asked to act on their behalf)
 - o 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.
- The grounds of appeal will only relate to:
 - whether or not a person has been ordinarily resident in Jersey for 12 months prior to making their first request
 - a determination by the Coordinating Doctor or the Independent Assessment Doctor that the person has, or does not have, decisionmaking capacity to request an assisted death OR that their wish for an assisted death is voluntary, clear, settled and informed.
 - a failure, or perceived failure, to make determinations or act in accordance with the process set out in law.
- Appeals must be made within 28 days of the approval decision.
- The decision of the Royal Court will be final. There will be no further right of appeal.

Step 6. Planning and preparation

- The Administering Practitioner may be the Coordinating Doctor or may be a practitioner who was not involved in the assessment process.
- The Administering Practitioner will support the person have an assisted death, including the planning and decisions involved.



- Although the person will have discussed their wishes with the Coordinating Doctor and the Independent Assessment Doctor during their assessments, the Administering Practitioner will confirm the person's wishes, including:
 - o the preferred method for an assisted death (see section 4c 'End of life')
 - how those present at the death will be prepared for what happens during the process of death
 - any cultural considerations and rituals that are important to the patient and their family
 - the location where the person wants to be at the end of their life.
 - Possible locations for an assisted death include:
 - private homes
 - o care and nursing facilities owned or managed by Government of Jersey (GoJ)
 - o care and nursing facilities not owned by GoJ (these may be privately owned, parish-owned or owned by a charity or community organisation)
 - hospital facilities
 - As part of the planning, the Administering Practitioner must confirm whether the person's preferred location is suitable.

Step 7. Prescribing the substance

- 'Assisted dying substance' refers to the medications used to bring about the person's death.
- The drug regime and protocols for assisted dying substances used in the different administration methods will be agreed by the Delivery and Assurance Board.
- Only the Administering Practitioner or another assisted dying professional may prescribe the substance.
- The Jersey General Hospital pharmacy will dispense medications used for the assisted dying substance. No other pharmacy will do so.
- Clear protocols for prescribing and dispensing the substance will be developed.
- The substance will be dispensed to the Administering Practitioner in a sealed and individually numbered box, clearly marked with a warning of its purpose.



Step 8. End of Life

- The Administering Practitioner will arrive at the agreed location, on the agreed date and time, to support the administration of the assisted dying substance.
- The person may choose to have friends and family present during the assisted death.
- Immediately before the person takes or is given the substance, the Administering Practitioner will carry out a final review to confirm that:
 - the person has decision-making capacity
 - the person continues to have a voluntary, clear, settled and informed wish to proceed
 - o the person is giving their final consent.
- If the Administering Practitioner is not satisfied that all these criteria are met, they will stop the process (except where the person made a waiver of final consent at Step 4, in which case the assisted death may proceed if the person lost decision making capacity *after* their request for an assisted death was approved).
- There are 4 different modes for an assisted death, the person will have agreed the most suitable mode with the Administering Practitioner in advance. The 4 modes are:
 - a. self-administration oral
 - b. self-administration intravenous delivery, triggered by the person
 - c. practitioner administration intravenous injection
 - d. practitioner administration orally
- If the person has chosen to self-administer the substance, then 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.
- Detailed protocols will be developed should an unexpected medical event occur, such as complications with the administration of the assisted dying substance. This could include the person taking longer to die than expected or issues with the administration of the substance

Step 9. After an assisted death

• Once the Administering Practitioner has confirmed the death of the person, they must then complete a post-assisted death administration form, which will record details of the death.



- In addition to the post-assisted death administration form, a medical certificate of the fact and cause of death (MCFCD) must be completed, as with any other death in Jersey.
- The MCFCD must be completed by someone other than the doctors involved in the approval or delivery of the assisted death. A group of Registered Medical Practitioners will be specifically trained to complete the MCFCD for an assisted death.
- The death would only be required to be reported to the Viscount if the death was not in accordance with, or suspected not to be in accordance with, assisted dying legislation.
- The process for the registration of the death and the burial or cremation of a person who has had an assisted death would be the same as with all deaths in Jersey.

Section 4. Regulation and oversight

- The Jersey Assisted Dying service:
 - a. must operate within the law and be seen to do so
 - b. must be safe, and
 - protect and safeguard people who may be vulnerable to coercion and control
 - o work to the highest standards of clinical safety
 - c. must meet the needs of care receivers and their families
 - d. must be of high quality, well-organised and easy to navigate
- The Jersey Care Commission (JCC) will provide independent regulation and oversight of the Jersey Assisted Dying Service.
- The JCC will inspect the assisted dying service at least once a year. The JCC will have the power to undertake announced or unannounced inspections.
- In the event the JCC finds alleged or confirm breaches of the law or its standards, the JCC will take action in accordance with its existing escalation and enforcement policy.
- The JCC will also have a duty to publish an annual report on assisted dying, which will include the number of assisted deaths and a profile of the requests for an assisted death.



Section 5. Responding to the consultation and next steps

Responding to the consultation

- You can view the full consultation document at www.gov.je/assisteddying.
- The public consultation will run from 17 October 2022 to 14 January 2023
- You can respond to the consultation by:
 - o completing the online survey
 - o attending a public meeting
 - o emailing a response to assisteddying@gov.je
- The comments provided in response to this consultation document will be given full consideration and, where appropriate, be reflected in the report and proposition to be lodged for debate by the States Assembly in early 2023.
- A consultation feedback report will be published alongside the report and proposition, detailing the feedback received.

Next steps

 The next steps for establishing an assisted dying service in Jersey are set out below. The dates may change depending on the feedback received:

Date	Action
17 October 2022 to 14 January 2023	Public consultation on detailed proposals
February 2023	Publication of consultation feedback report
March 2023	States Assembly debate on detailed assisted dying proposals
March 2023 - 2024	Preparation of draft law



Late spring / early Summer 2024	States Assembly debate on draft law
Early summer 2024 to end 2025	Implementation period for assisted dying service in Jersey, including: training of health professionals development of website and public information set up of service and regulatory regime
End 2025	Assisted dying legislation comes into effect