Government of JERSEY

assisted dying information session

May 2024

Gouvèrnément d'JÈRRI

Overview

Section 1: Background

Section 2: Proposals for Assisted dying in Jersey

Government of JERSEY

1. Background

Gouvèrnément d'JÈRRI

Public and health and care professional information sessions during lodging period

Health and care professionals:

- 2 x HCS staff dedicated sessions
- 2 x all on-Island health and care professional briefings

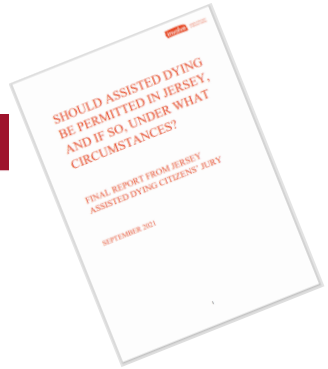
Public sessions:

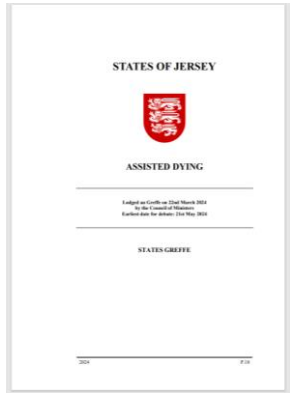
- Tuesday 26 March 2024, 12pm to 12.45pm and 1pm to 2pm (St Paul's Centre, St Helier)
- Thursday 25 April 2024, 6.30pm to 8.30pm (St Saviour’s Parish Hall)
- Thursday 2 May 2024, 5pm to 7pm (St Clement's Parish Hall)
- Tuesday 7 May 2024, 6.30pm to 8.30pm (St Helier Town Hall)
- Tuesday 14 May 2024, 7pm to 8.30pm (Les Quennevais School)

States Members:

- Weekly ‘drop in’ sessions
- 3 x full briefing sessions

Development of Assisted dying proposals





2018 2021 2022 2023 2024

extensive consultation and engagement on and off-island

www.gov.je/assisteddying

What happens next?

March – May 2024
Lodging period

21 May 2024
States Assembly debate on proposals

Proposals for assisted dying in Jersey agreed/rejected

Preparation of draft law
[& further development work, including survey HCP re participation in AD]

November 2025
States Assembly debate draft law

2026- 2027
Implementation period

Spring/summer 2027
Assisted dying law comes into effect

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 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 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.

Palliative & end of life care

- In jurisdictions where assisted dying is permitted, the majority of people requesting an assisted death are also receiving palliative care (75%+).

Ongoing work in Jersey

- Palliative and End of Life Care Strategy published in Nov ’23 (partnership between GoJ, Jersey Hospice and End of Life Care Partnership)

- 2023 Government Plan committed to annual additional spend of £2-3 million per year in end of life and palliative domiciliary care provision in Jersey

Proposition commitment

- Proposition on draft law to be presented to the Assembly (Nov ‘25) will ask Members to agree, that legislation permitting assisted dying should not be brought into force until the Assembly is satisfied:
  - additional investment is supporting improvements in quality and availability of end of life and palliative care services.

Often cited that introduction of assisted dying erodes palliative and end of life care. UK Select Committee clear this is not the case. Some evidence of improvement as ‘spotlight effect’

Government of JERSEY

2. Assisted dying in Jersey

Gouvèrnément d'JÈRRI

Eligibility criteria

- Over 18 years
  - all other jurisdictions (except Netherlands / Belgium)

- Jersey resident (12 months ordinary residence)

- Voluntary, clear, settled and informed wish

- Decision-making capacity:
  - whole process
  - Waiver of final consent
  - capacity test in law

- PLUS health criteria

Eligibility criteria

Not mental health (unless qualifying physical condition and capacity)

Route 1 – terminal illness

- Diagnosed with a **terminal illness**:
- Giving rise to, or is expected to give rise to unbearable suffering (i.e. current suffering or expectation of future suffering)
- reasonably expected to cause person's death within **6 months** or **12 months** for neurodegenerative condition (e.g. motor neurone disease, or Parkinson's)

OR

Route 2 – unbearable suffering

- Has an **incurable physical medical condition** that is giving rise to **unbearable suffering** (i.e. suffering here and now)
- That cannot be alleviated in **a manner the person deems tolerable** (acknowledges person's choice to reject treatment options)

Jersey Assisted Dying Service

- delivered by HCS, as a separate service
- free to access
- Jersey Assisted Dying Service will:

provide information to all about assisted dying (AD)

support people to navigate the process
and
support loved ones (including access to wellbeing & bereavement support)

coordinate and deploy professionals engaged in the assisted dying process (+ provide wellbeing support)

Assisted dying as a separate service

"The BMA does not believe that assisted dying should be integrated into existing care pathways (whereby a patient's GP, oncologist or palliative care doctor would, at the patient's request, provide assisted dying as part of the standard care and treatment they provide).

In the BMA's view, assisted dying should be arranged… through a different pathway.

The model proposed in Jersey…provides an example of how this could work.

In our view, this would be better for doctors and for patients and would help to ensure consistency, and facilitate oversight, research and audit of the service."

British Medical Association statement

Assisted Dying Assurance and Delivery Committee

- Will oversee the clinical and corporate governance of the Jersey Assisted Dying Service, ensuring that:

the service is well-run	the service is safe
there is fair access to the service	the standards of care are high

- sub-committee for Advisory Board

- members may include:
  - independent Chair
  - relevant professional leads
  - representatives of end-of-life services / care (e.g.: hospice services; home care services etc). On or off-island.
  - patient representatives

Health and care professionals ‘opt in’ to work for Jersey Assisted Dying Service

Opt-in registration: to practice an assisted dying practitioner role, professional must:

a. choose to opt-in
b. be registered with the JCC (and 12+ months post-UK registration)
c. complete assisted dying training
d. meet competencies framework requirements

When registered, they must: renew registration on annual basis; undertake refresher training every 3 years; complete a declaration of interests.

Assisted dying practitioner roles

- **Care Navigator –** non-clinical role, administrative support and point of contact
- **Assessing doctors:**
  - **Co-ordinating Doctor** – does the first assessment and approves/declines request
  - **Independent Assessment Doctor** – does the second assessment
- **Multidisciplinary team –** group of health and care professionals including nurse and social worker to support assessing doctors to make their decision

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- **Pharmacy professional** – prepare and dispenses assisted dying substance, works within JGH
- **Administering practitioner** – supports the person with the assisted death

Right to refuse to participate (inc conscientious objection)

- Law will state that no-one can be compelled to **directly participate** in assisted dying
- Not participating must be in accordance with UK professional guidance (ie. not express their personal beliefs in an appropriate way)

Within scope of 'right to refuse'

- support a person to access to AD
- undertake any specified role
- directly support the administration of the assisted dying substance
- supporting opinions or assessments (e.g. capacity test or ancillary tests such as pulmonary function tests)
- permission to allow a resident to have AD on the premises (e.g., in a care home or hospice)

NOT within scope

- providing usual care to a person who has requested AD
- administrative tasks (e.g., undertaking residency check)
- delivery of equipment or medical supplies for use in AD

Talking about assisted dying

- Jersey Assisted Dying Service will give information to people thinking about assisted dying, their family and health and care professionals

- Person can self-refer to Jersey Assisted Dying Service – or via health professional

- The Law won't stop health professionals talking about assisted dying to their patients…

- …But they will have training and advice on how to have conversations about assisted dying (Appropriate Conversations Guidance) - including care staff

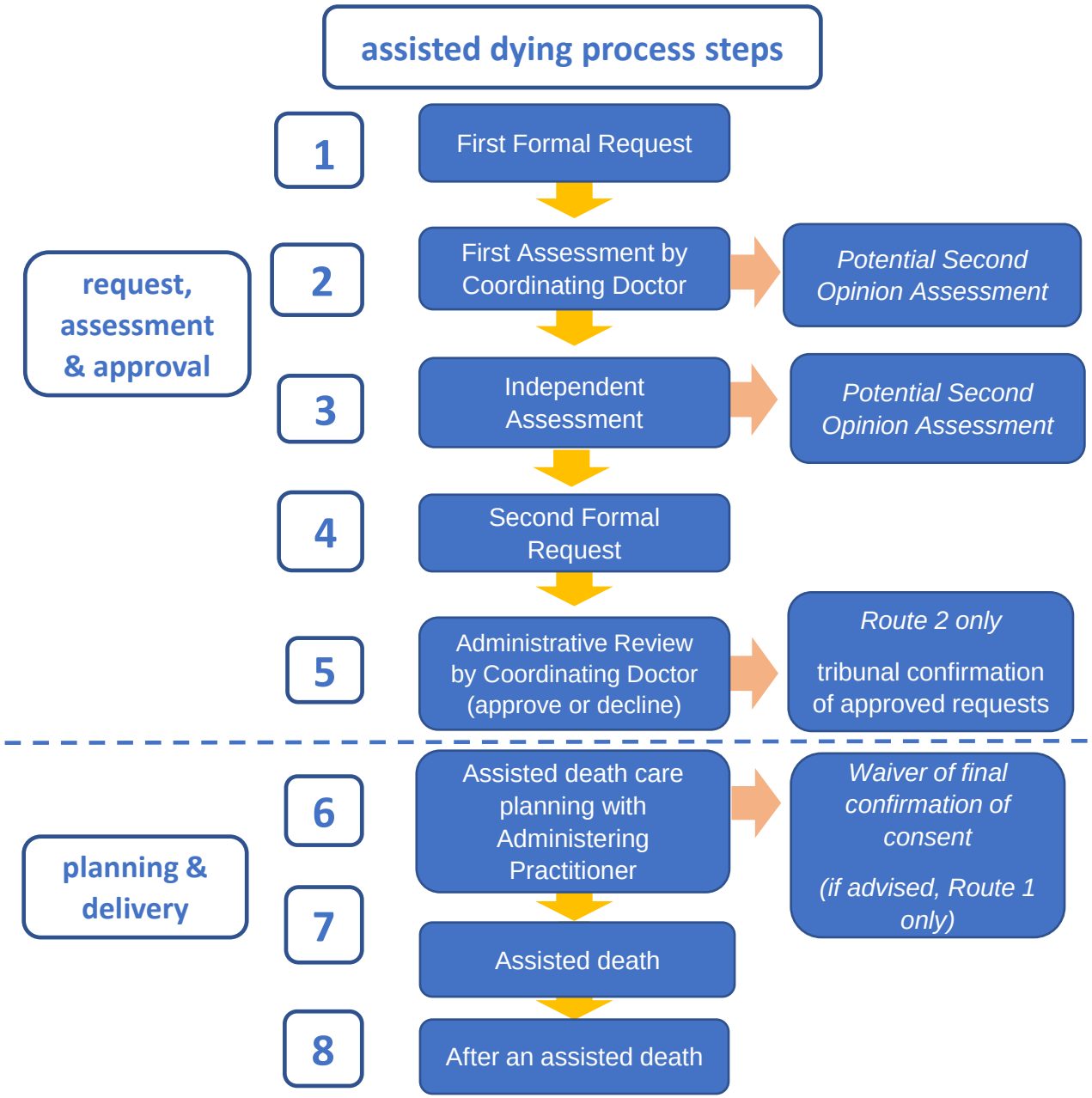
➢NMC and GMC support this position

Assisted dying process

- Person in control
  - moves to each step at own pace
  - can withdraw request at any time

- Minimum timeframe
  - Route 1 (terminal illness) at least 14 days
    - *(Unless life expectancy less than 14 days)*
  - Route 2 (unbearable suffering) at least 90 days

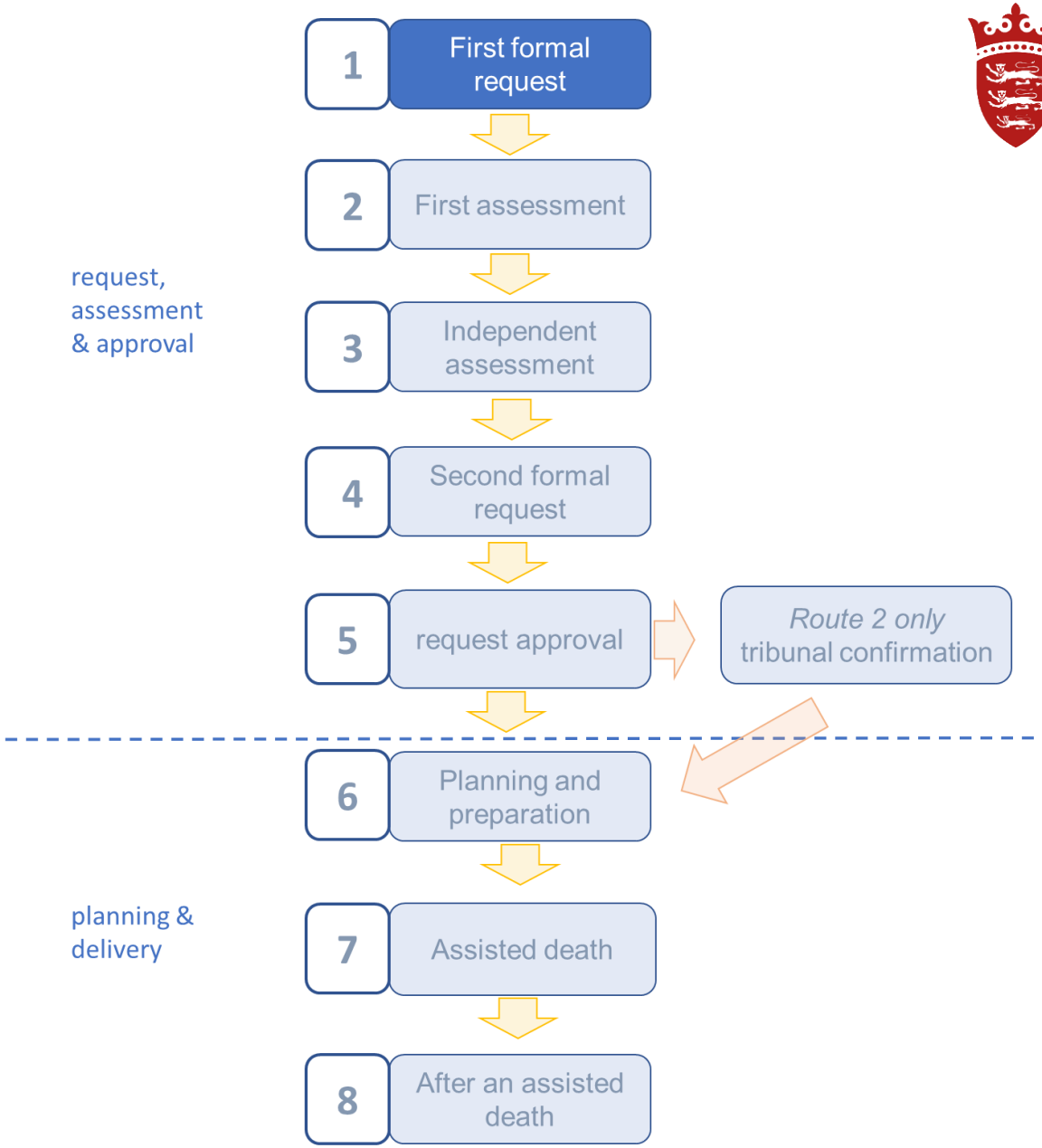
➢period of reflection



Step 1: First formal request

- Starts the process
- Person asks for an assisted death
- Request is recorded in writing

➢Communication and interpretation support provided – as required – throughout the process



Step 2: First assessment

Coordinating Doctor must:

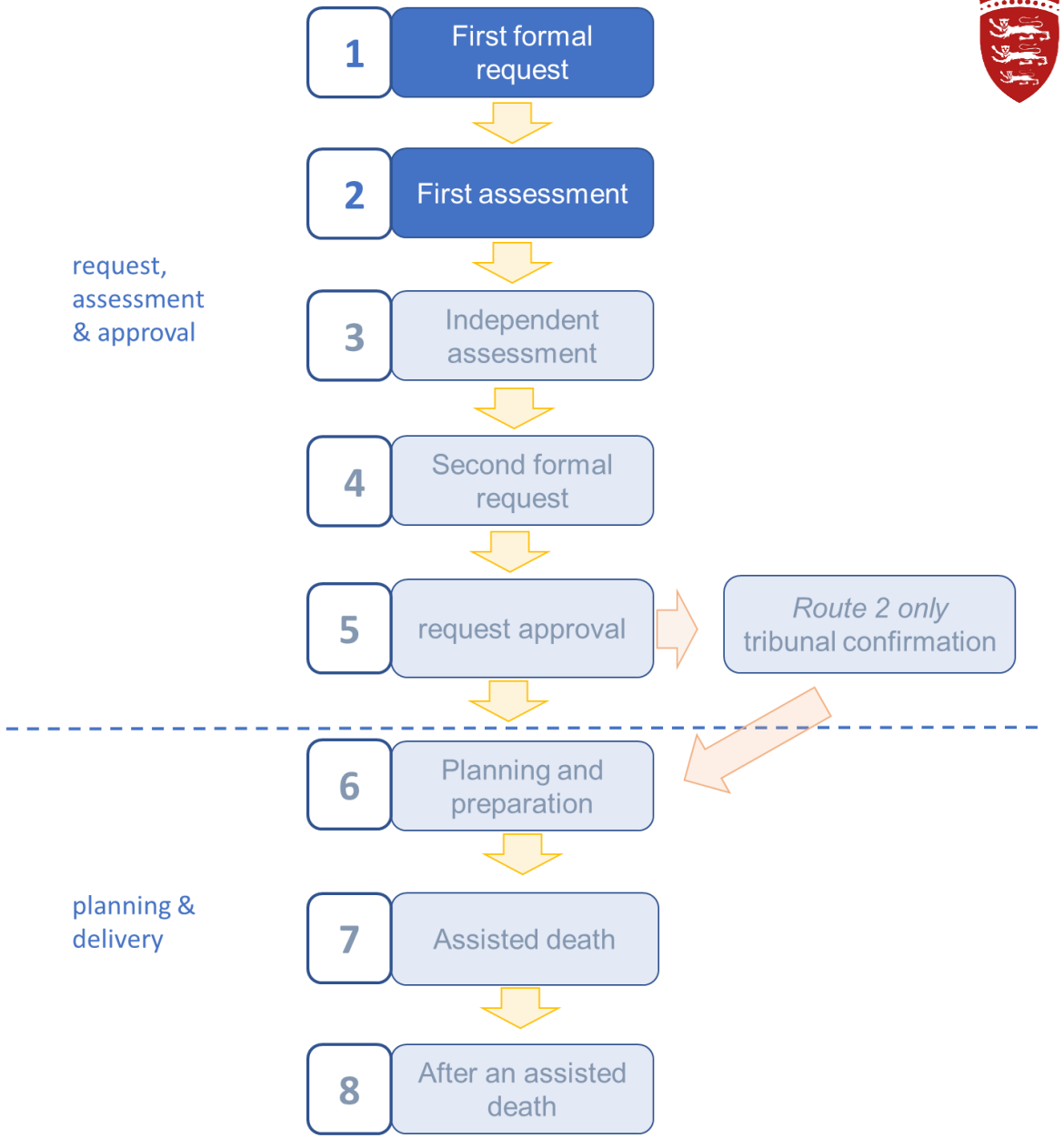
- explore reasons for request
- explore all care / treatment options

+ make sure person is fully informed

- encourage involvement of family and loved ones (if person declines, must understand that may impact ability to make determination)
- seek supporting opinions / assessment from other professionals if needed to make their assessment (eg: capacity; life expectancy; treatment options; coercion)

Then

- decide if person meets eligibility criteria

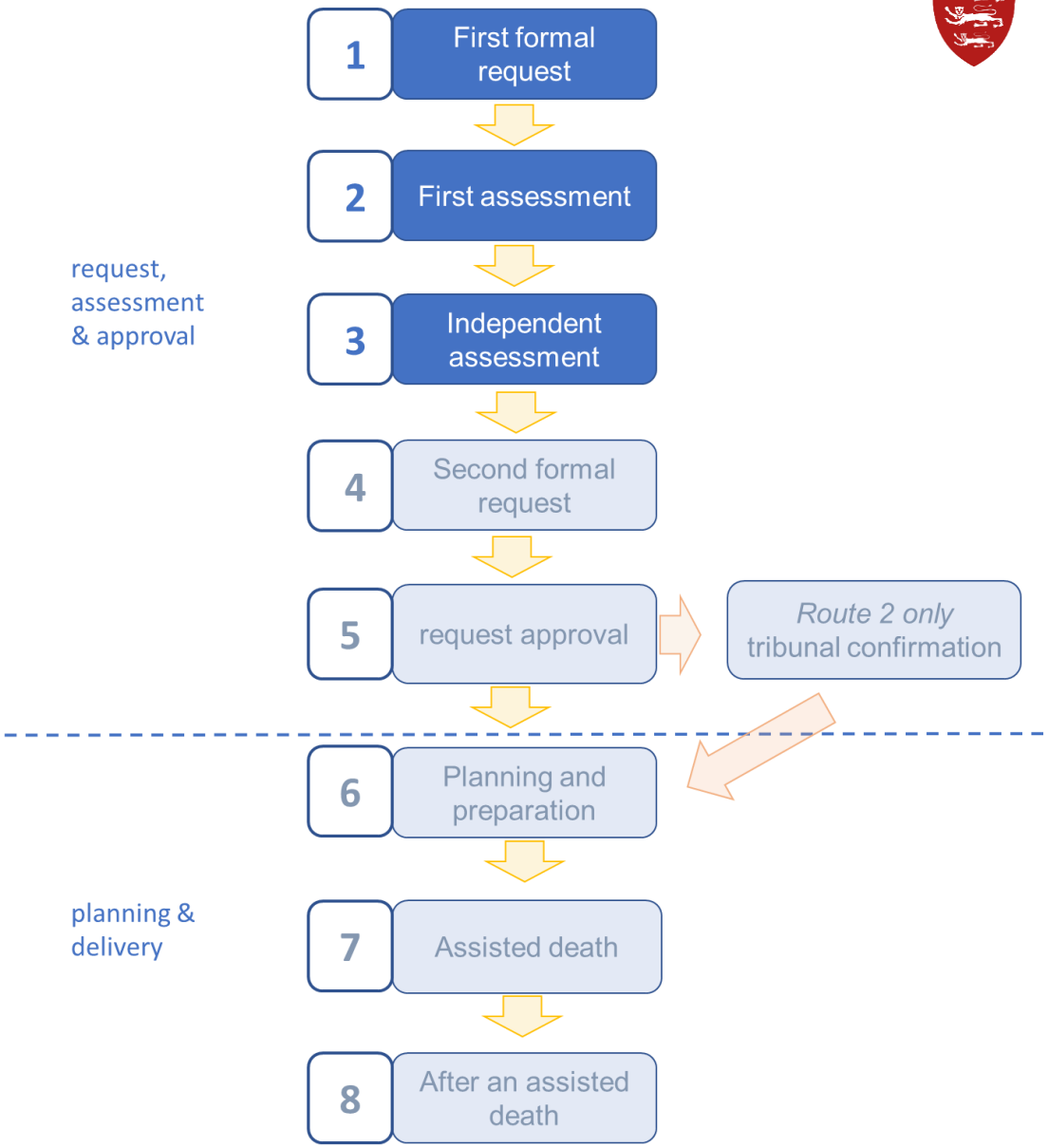


If person is found ineligible

- Process stops
- Person offered support
- Person may request second opinion assessment at step 2 or step 3

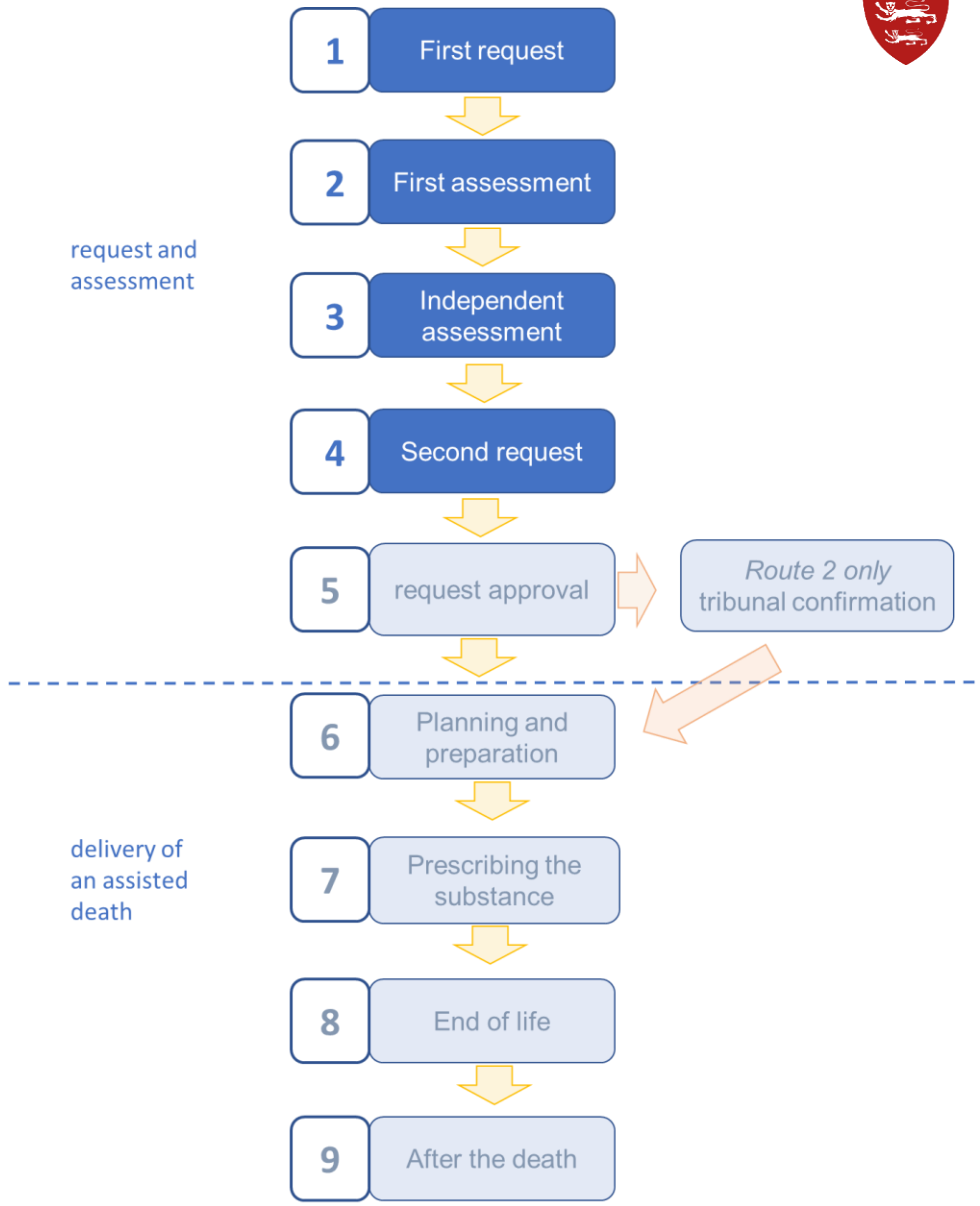
Step 3: Independent assessment

- Same process as first assessment
- A separate assessment:
  - may access supporting opinions
  - may not access first assessment record
- Must also decide person is eligible for process to continue - otherwise process stops
- (Assessing doctors not required to be a specialist in the medical condition(s) of the persons but, they must seek opinion of experts as required.)



Step 4: Second formal request

- A written declaration to confirm enduring wish for assisted death
- Signed by a witness who attests that, to best of knowledge the person signing declaration did so freely
- Witness must know the person but not be related or set to gain from their death (eg: attending carer, friend etc)



Step 5: Request approval

Two different approval routes proposed:

- Route 1 (terminal illness) – assessment by 2 doctors only (Coordinating Doctor approves having reviewed process and paperwork)
- Route 2 (unbearable suffering) – assessment by 2 doctors + tribunal confirmation of Coordinating Doctor's approval

- *Route 1: Doctor approval, parallels with current end of life practice*
- *Route 2: Additional step acknowledges shift in trajectory of person's life*

- No expiry on approval

request, assessment & approval

1 First formal request

2 First assessment

3 Independent assessment

4 Second formal request

5 request approval

Route 2 only tribunal confirmation

6 Planning and preparation

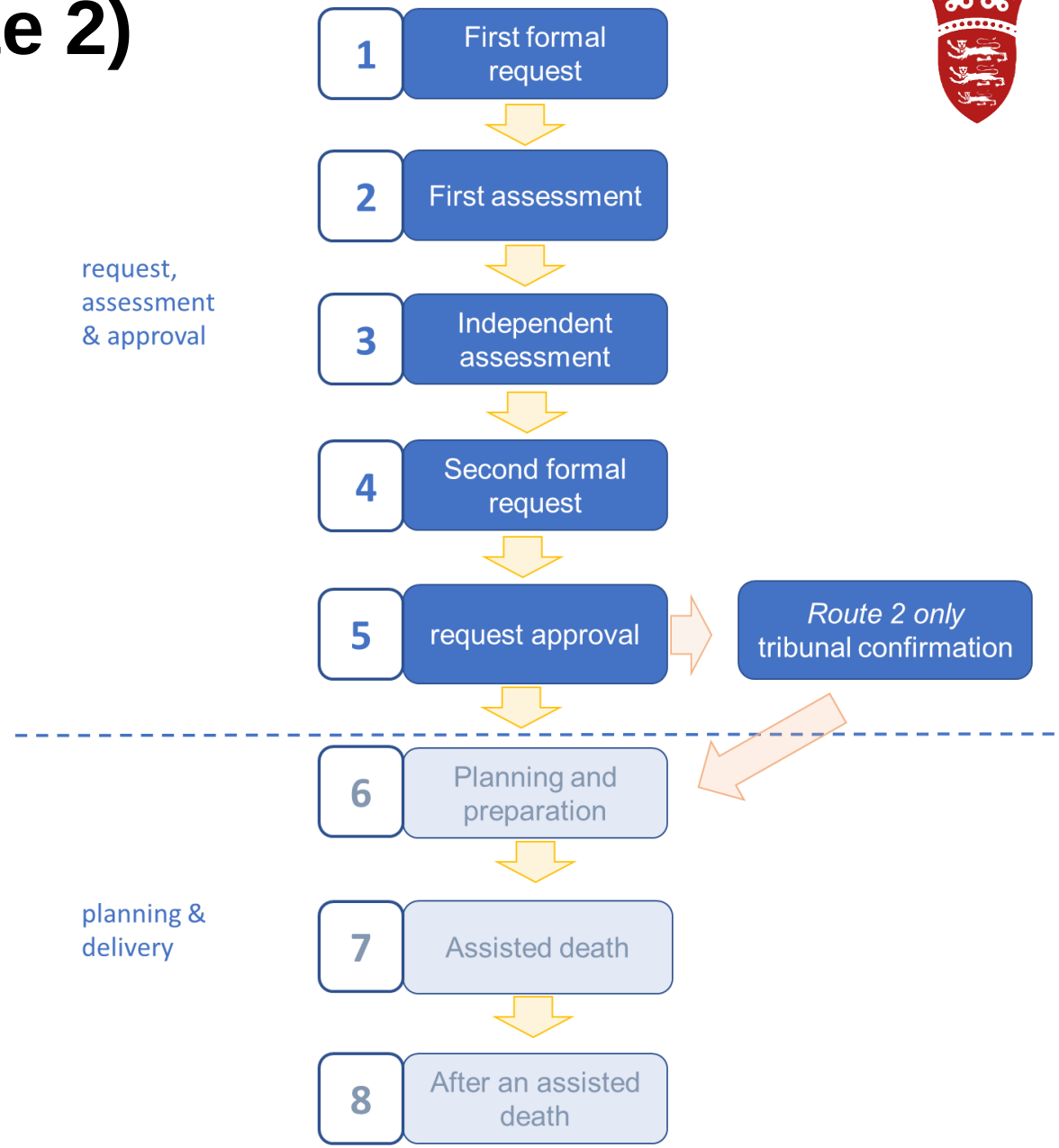
planning & delivery

7 Assisted death

8 After an assisted death

Step 5: Request approval (Route 2)

- Tribunal will review all decisions by Coordinating Doctor to approve assisted dying (but not to reject – can move to appeal)
- Reviews all relevant information + may request further information, evidence or assessments
- Each Tribunal panel will consist of a legal member, a medical member and a lay member
- Must reach a decision within 30 days



Step 5: Appeals

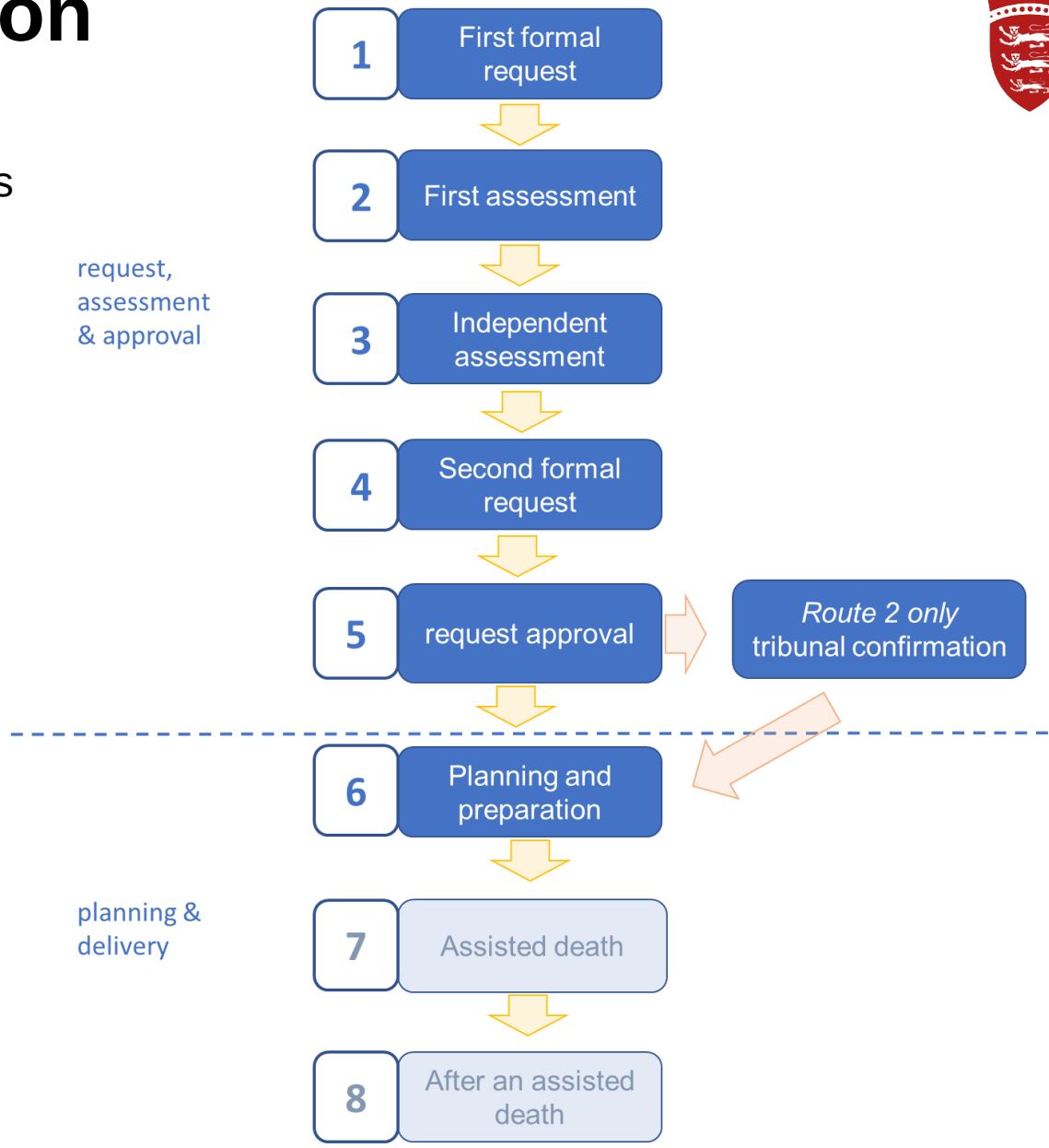
Additional safeguard to support public confidence: not provided in other jurisdictions (except some Australian States)

- Appeals may be made to Royal Court by:
  - the person who has requested an assisted death (or someone they have asked to act on their behalf)
  - any other person with special interest in the care & treatment of the person (family member.)
  - NOT a person/organisation who is unconnected – e.g. campaigning organisation
- Grounds of appeal may relate to:
  - residency
  - decision-making capacity
  - 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
- Minimum 2 working days between approval and assisted death (Step 7) to allow for 3rd party appeal to be made

Step 6: Planning and preparation

- Administering practitioner work with person to agree details of assisted death, including:

- Location may be private home, care home or Government facility (e.g. hospital)
  - Administering practitioner to approve suitability of location in advance
- Other details of the assisted death:
  - Who will be present
  - Mode of administration
- Assisted death care plan *may* include:
  - Waiver of final confirmation of consent
    - Route 1 (terminal illness) only
    - Person can choose to make if expected to lose capacity
    - Must do so *after* assessment and request approved
  - Confirmation of consent to proceed
    - Consent for practitioner to intervene in the case of any medical complications
    - For example, if self-administered orally, practitioner may proceed to IV administration

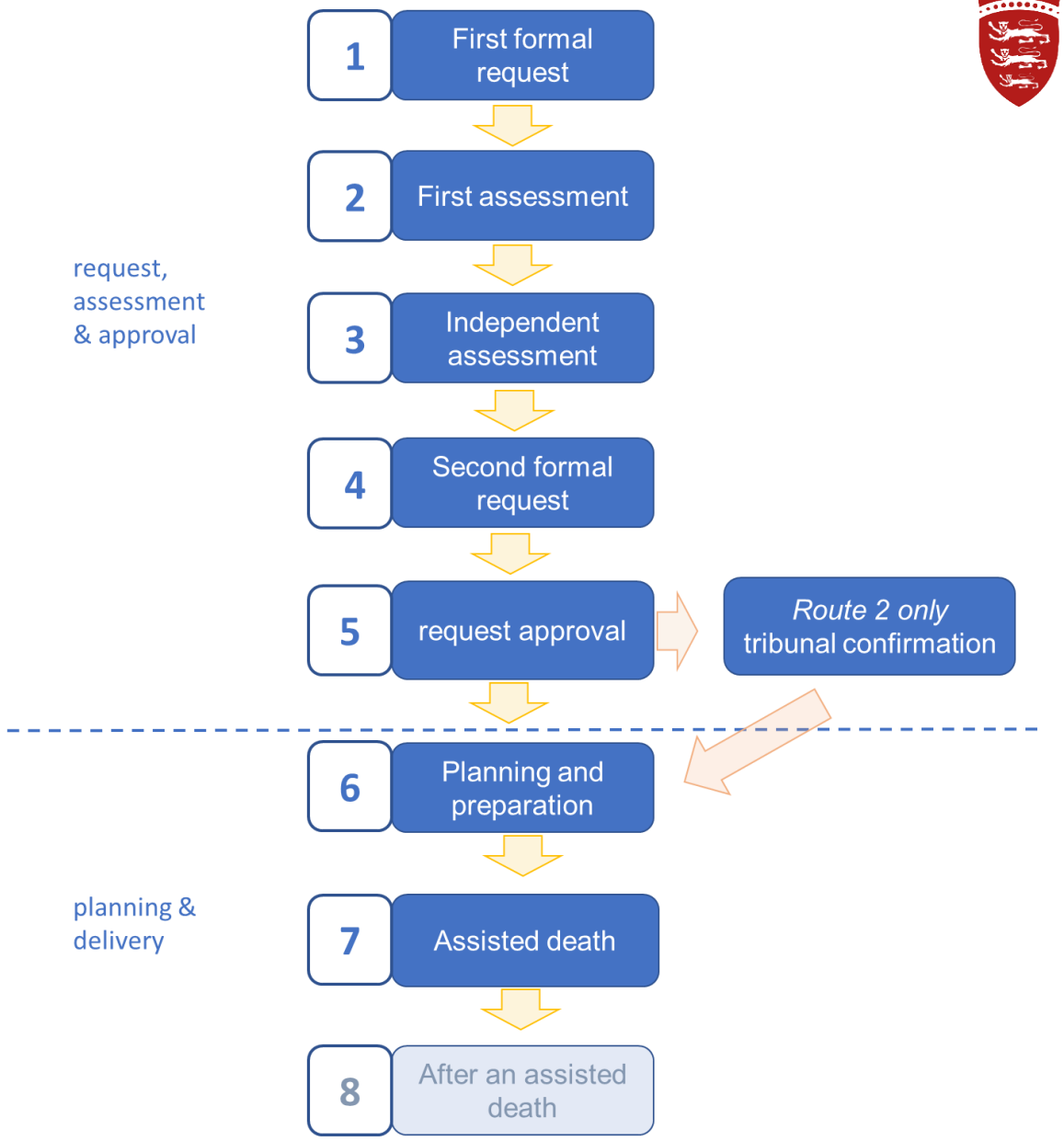


Prescribing the substance

- 'Assisted dying substance' refers to the medications used to bring about the person's death
  - *Exact drug regimen to be confirmed by Assurance and Delivery Committee*
- Only the Administering Practitioner or another assisted dying professional may prescribe the substance
- Jersey General Hospital pharmacy will compound, store, pack and dispense
- Clear protocols for prescribing and dispensing the substance –chain of responsibility for medications

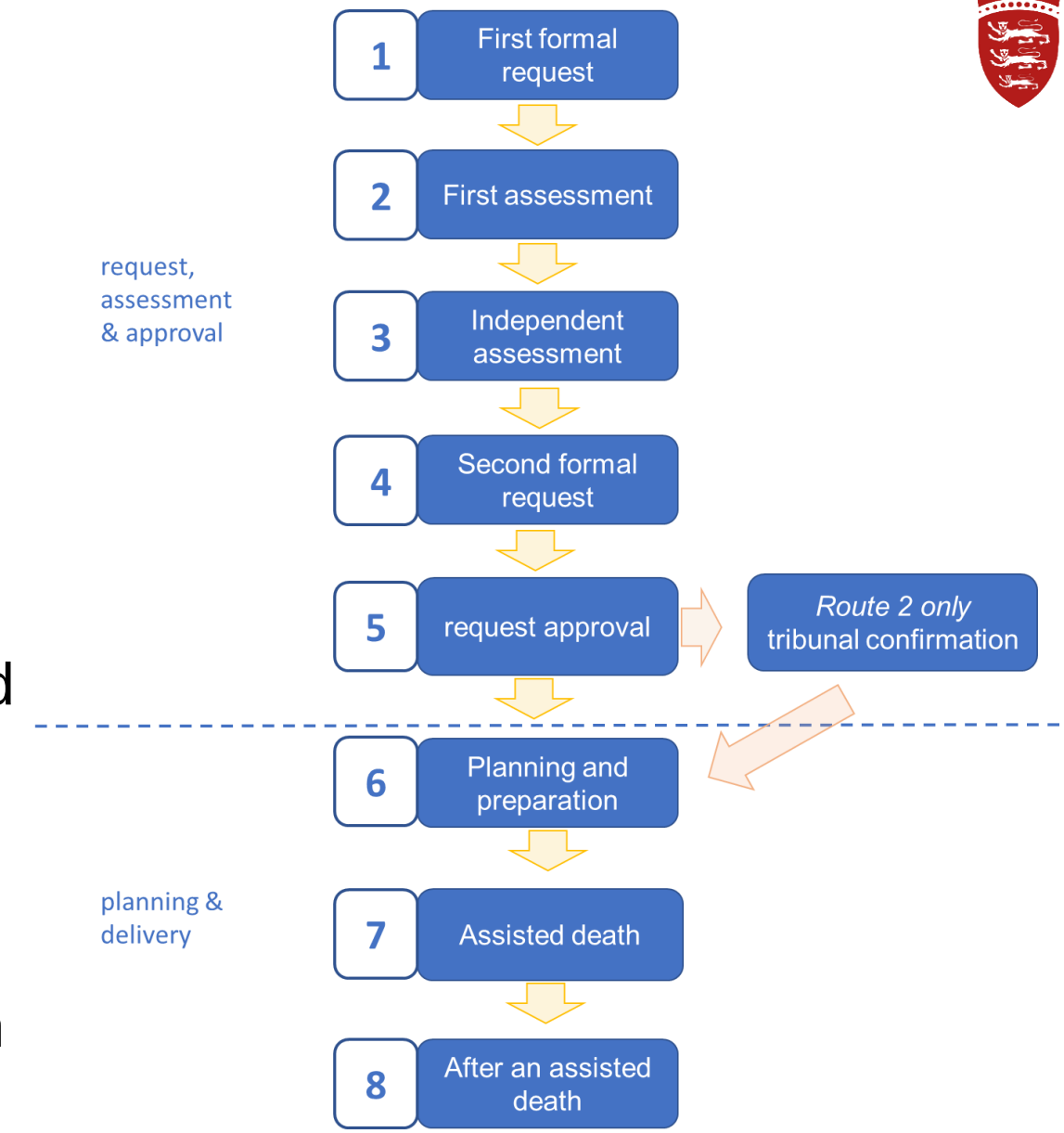
Step 7: Assisted death

- Administering Practitioner and other member of the Assisted Dying Service to attend
- Administering Practitioner will carry out final review of:
  - decision-making capacity
  - voluntary, settled and informed wish
  - consent to proceed (unless waiver of final consent)
- Mode of assisted death
  - Self-administered or practitioner-administered
  - Oral administration or IV
  - If self-administered, family member may support person, under supervision
- Administering Practitioner to remain with or nearby the person throughout the process



Step 8: After an assisted death

- Administering Practitioner will confirm the death and complete a form with information about the death
- A separate doctor will complete the death certificate (MCFCD)
- The death certificate will describe the death, the medications used and the reason the person was eligible for assisted dying
- Viscount involvement ONLY if not in accordance with law
- Death will be treated as any other death in terms of cremation/burial etc.



Regulation and oversight

Jersey Assisted Dying Service

- follow the law
- be safe
- safeguard people
- meet the needs of people and their families
- be of high quality and well-organised

Assurance and Delivery Committee

- develop service / clinical standards and ensure compliance
- develop mandatory training and guidance
- develop competencies framework and referral's threshold (in consultation with professional bodies)
- establish post-death review panel
- publish a yearly report

Jersey Care Commission

- register assisted dying service
- inspect the assisted dying service
- develop service standards
- recommend safety and quality improvements
- can shut down service, if serious failings are found

Questions?

www.gov.je/assisteddying

Additional slides for Q+A

www.gov.je/assisteddying

Proposition

Five key paragraphs voted separately

States Assembly to determine:

- if we progress to law drafting plus core eligibility criteria and process (para a)
- whether assisted dying permitted for:
    - Route 1 “terminal illness only” (para b)
    - Route 2 “unbearable suffering” (para c)
- Appendix inc: supplementary safeguards and process issues

➢Can be amended by States Members prior to debate

2023 Government Plan – End of Life/palliative care additional funding

Health and Community Services - New Revenue Expenditure Growth						
Allocated or Held		£'000	2023	2024	2025	2026
in Reserves	Reference	Description	Estimate	Estimate	Estimate	Estimate
Allocated	I-HCS-GP23-001	On-boarding Clearances	115	115	115	115
	I-HCS-GP23-002	Placements and Off-Island Medical Care	5,000	5,000	5,000	5,000
	I-HCS-GP23-003	Agreed Contractual Changes	1,372	1,372	1,372	1,372
	I-HCS-GP23-004	Commissioned Services	379	379	379	379
	I-HCS-GP23-005	Staffing Pressure	2,007	2,131	2,171	2,221
	I-HCS-GP23-006	End of Life and Domiciliary Care *	2,029	2,851	3,014	3,076
	I-HCS-GP23-007	Mental Health Development and Gender Pathway	685	1,127	1,127	1,127
	I-HCS-GP23-008	Essential Recruitment	1,063	1,058	1,061	1,058
		Jersey Care Commission - Regulation				

*Confirmed 2023 actual spend £1,568,000

Source: Government Plan 2023 to 2026 Annex.pdf

Estimated costs (1)

- Indicative costs only, updated cost estimate to be developed once Assembly has agreed proposals, to be presented alongside draft law in 2025
- Proposals set out:
  - Implementation costs
  - Ongoing annual cost estimates

- Set-up and implementation (one-off cost)

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**

Estimated costs (2)

- Ongoing costs: some elements fixed, other vary dependent on number of requests and assisted deaths
- Cannot make detailed projections of numbers of assisted deaths, but estimates based on assisted deaths as a % of all deaths in other jurisdictions: possible range 6 (Oregon – 0.6%) to 38 (Canada 4.1%) per year

Number of assisted deaths per year	**Cost per assisted death (staffing + other fixed costs)**	**Annual ongoing cost for assisted dying in Jersey** (based on no. of assisted deaths per year)
6	£ 107,969	£ 647,814
13	£ 62,540	£ 813,020
25	£ 43,849	£ 1,096,225
38	£ 36,922	£ 1,403,036

BMA position on assisted dying, if law to change:

General

- doctors ‘opt in’ to provide assisted dying
- a right to refuse to carry out activities directly related to assisted dying, for any reason

Protection from discrimination and abuse

- statutory protection from discrimination
- provision for safe access zones

Delivering an assisted dying service

- assisted dying as a separate service
- an official body to provide information for patients
- adequate funding and equitable access

Oversight and monitoring

- open and transparent regulation
- the collection and publication of data
- a review of all assisted deaths.

Assisted dying as a separate service

“The BMA does not believe that assisted dying should be integrated into existing care pathways (whereby a patient’s GP, oncologist or palliative care doctor would, at the patient’s request, provide assisted dying as part of the standard care and treatment they provide). In the BMA’s view, assisted dying should be set up as a separate service that would accept referrals from other professionals and/or self-referrals. Doctors who wanted to do so could still assist their own patients, but this would be arranged, and potentially managed, through a different pathway. In our view, this would be better for doctors and for patients and would help to ensure consistency, and facilitate oversight, research and audit of the service.”

Source: Physician assisted dying (bma.org.uk)

Assessing suffering

- Assessing doctors must determine that:
  a. there is suffering (whether physical and / or mental) OR that suffering is expected to arise [R1], 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.

- Will not be required to determine whether suffering is unbearable (acknowledging this is entirely subjective and individual). Assessing doctor required only 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).
  c. be satisfied the person understands that suffering can fluctuate and their ability to tolerate suffering can change

- Suffering will be defined as:
  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.

- Suffering arising solely from:
  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'

  will not satisfy the requirements under law even where the person has a physical medical condition because the suffering <u>does not arise from the physical condition</u>

Causes of suffering (1)

Causes of suffering may include:

- the physical medical condition itself and the impact of that physical medical condition:

Person A: 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.

Person B: 5 years ago, a person was involved in a serious motor vehicle accident. They suffered paralysis from the neck down and chronic pain. They have 24h care support. And unbearable suffering caused by chronic pain, 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.

Causes of suffering (2)

- the treatment provided for the physical medical condition

Person C: Has 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

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

Person D: 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)

Suffering as a result of mental illness

- the presence of mental illness (such as depression) is not uncommon in people at end of life.
- Assessing doctor will need to determine if any mental anguish/suffering arises from:
  a. mental illness alone
  b. a combination of their mental illness and physical condition

- Where there is uncertainty as to the cause of mental suffering, referral to a relevant professional - this may include a psychiatrist or psychologist.