

STATES OF JERSEY



ASSISTED DYING (P.18/2024) – ADDENDUM

Presented to the States on 7th May 2024
by the Minister for Health and Social Services

STATES GREFFE

COMMENTS

Engagement with disabled islanders and islanders with long-term conditions: summary of feedback on assisted dying ‘Route 2’ proposals

Introduction

1. Between 17 and 30 April 2024 Government of Jersey (“GoJ”) policy officers, with support from third sector organisations, met with disabled islanders and islanders with long-term conditions to gather their views on assisted dying with a particular focus on the ‘Route 2 – unbearable suffering’ proposals.
2. For a person to be eligible under ‘Route 2 – unbearable suffering’ they must have been diagnosed with an incurable physical medical condition that is giving rise to unbearable suffering that cannot be alleviated in a manner the person deems tolerable.
3. This report describes the engagement process and summarises the feedback received.
4. This report does not respond to the themes raised, seek to qualify them or correct any inaccuracies or misconceptions presented by participants (whether those inaccuracies and misconceptions apply to the proposals as published, or to practice and evidence related to assisted dying in other jurisdictions).

Background

5. Two phases of public consultation on assisted dying had previously taken place in 2022 and 2023. This included consultation with disabled islanders and islanders with long-term conditions:
 - a. 2 x dedicated accessible consultation meetings (in wheelchair-accessible venues and with communication support, including BSL interpreters and on-screen speech to text captions)
 - b. publication of accessible formats of the summary proposals including Easy Read and British Sign Language (BSL)
6. The Assisted Dying in Jersey Ethical Review Report, published in November 2023:
 - a. noted that consultation with disabled islanders on assisted dying had already taken place
 - b. recommended that GoJ carried out additional engagement to seek the views of disabled islanders specifically on ‘Route 2 – unbearable suffering’. The review authors noted: *“it would seem appropriate to seek their [disabled islanders’] views on the final specific proposals, particularly if route 2 is*

included as this appears to offer assisted dying options particularly or exclusively to them.”

7. The assisted dying report and proposition (P18/2024) commits to undertaking that additional engagement and to lodging a feedback report as an addendum to that proposition. The feedback report is to be lodged 2 weeks prior to the scheduled date (by 7 May for debate on 21 May).

Overview of engagement process

Purpose of engagement process

8. The principal aim of the engagement process (17 and 30 April 2024) was to seek views of disabled islanders and islanders with long-term health conditions on:
 - a. the inclusion of ‘Route 2’ in the assisted dying proposals
 - b. the potential impact of ‘Route 2’, including the direct impact on disabled islanders and islanders with long-term health conditions and impact on perceptions of disability in Jersey.
 - c. possible ways to mitigate negative impacts.
9. SEE APPENDIX 1 for the detailed discussion guide

Overview of sessions

10. The engagement process was targeted, both in terms of participants (disabled islanders / islanders with long-term health conditions) and topic for discussion (feedback on ‘Route 2’).
11. GoJ policy officers worked in partnership with organisations who support disabled islanders and islanders with long-term conditions to plan the engagement process and invite participants to take part in small group discussions [see table below].
12. In addition to the small group discussions, there was one meeting that was open to any disabled islander / islander with a long-term health condition, their family, friends or carers. 1-2-1 interviews were also offered to people who were not able to attend the small group discussions but which to provide feedback. Only one person opted for a 1-2-1 interview.
13. Participation in the group discussion sessions was promoted via the partner organisations directly to their clients/service users.
14. The open meeting was listed on gov.je/assisteddying and promoted via:
 - a. Government of Jersey social media channels

- b. Customer and local services voluntary and community sector weekly update
- c. Government of Jersey employee networks: disability; diversity, equity and inclusion; and neurodiversity networks
- d. note to local media organisations.

Participants

- 15. The engagement process was primarily aimed at disabled islanders and islanders with long-term conditions (approximately 80% of total participants) with a secondary focus on friends, family, carers and representatives of disabled islanders and islanders with long-term conditions (approximately c.20% of total participants).
- 16. Those participants included people with a range of:
 - a. ages, including younger and older adults (c. aged 20 to 90+)
 - b. health conditions, including physical disabilities, sensory impairments, long-term and terminal conditions, learning disabilities and mental health conditions
 - c. views towards assisted dying

Organisation	Date	Format	Attendees
Enable Jersey	25 April	Small group discussion	10
Jersey Employment Trust (JET) / Acorn	23 April	Small group discussion	5
Jersey Employment Trust (JET) / Acorn	24 April	Small group discussion	3
Older Person’s Living Forum	17 April	Small group discussion	11
EYECAN	29 April	1-2-1 interview	1
Public engagement session (supported by Enable Jersey)	30 April	Open meeting	8

Feedback from engagement sessions

- 17. This report summarises the feedback provided by people who chose to participate in the engagement process. It is important to note that this was a self-selecting group of people.

18. The discussions were qualitative in nature, hence the feedback is not quantitative (ie. it does not set out of percentage of participants who held certain views). However, this report does, where relevant, provides broad indications of where the views expressed were held by a significant majority or minority of participants.

Summary of views towards assisted dying

19. The participants that took part (both disabled islanders/islanders with long-term conditions, and their family members, carers and representatives) held a range of views towards assisted dying. Overall:
- a. a significant majority of participants were in favour of the ‘Route 1 – terminal illness’
 - b. around half the participants also supported the ‘Route 2 – unbearable suffering’
 - c. a minority did not support assisted dying in any form.

Summary of feedback in **support** of ‘Route 2 – unbearable suffering’

20. Approximately half of the participants were supportive of ‘Route 2’. The key rationale for this support is summarised below:
- a. Some participants expressed the view that ‘Route 2’ should not be rejected on the grounds of ‘protecting disabled islanders’ who are suffering, which was viewed as overly paternalistic
 - *“this isn’t about disability, it’s about suffering, and choice for people who feel that they can’t go on.”*
 - b. ‘Route 2’ is about giving a valid option to a very small number of islanders, who have lives that are unimaginable in terms of their suffering
 - *“There would be less than a handful of people a year who want this, but why deny them the opportunity?”*
 - c. Society has always treated disabled people differently, and continues to do so, why would this service change things?
 - *“Some people already see our lives as having less value, this won’t change that.”*
 - d. Those with unbearable suffering who don’t have a terminal illness/ short life expectancy, are arguably more in need of the option of assisted dying.
 - *“For these people it’s potentially decades of unbearable suffering, not just 6 months.”*

Summary of feedback **opposed** to ‘Route 2 – unbearable suffering’

21. Around half of the participants were opposed to ‘Route 2’. Of these participants, a majority were supportive of ‘Route 1’ but not ‘Route 2’ and a small number did not support assisted dying in any form. Key rationale for this opposition is summarised below:
- a. Assisted dying should be about choice at the end of life, Route 2 is far beyond end-of-life provision:
 - *“Assisted dying should be about ending the suffering of those who are already dying”*
 - b. Concerns about how the assessment and approval process for ‘Route 2’ would work in practice, including amongst some participants who agree with ‘Route 2’ in principle:
 - *“Route 1 is clear and straightforward, but Route 2 is a minefield.”*
 - c. Concerns about key eligibility being based on subjective criterion – i.e. the extent of a person’s suffering
 - *“You can’t quantify unbearable suffering, how can someone else know your suffering?”*
 - d. Concern that the risks associated with ‘Route 2’ are too great / the general concerns associated with assisted dying are amplified with ‘Route 2’ (for example, the risk of coerced people being wrongly found eligible for an assisted death)
 - *“Even if we only get it wrong for 1 or 2 people, that’s too many. Too much of a risk.”*
 - e. Potential negative impact on the emotional wellbeing professionals who support someone to die under ‘Route 2’, given that the person may not be close to the end of their life.
 - *“I am concerned about the mental health of practitioners before, during and after, not just at the time, but for a very long time afterwards.”*
 - f. Impact on society in the longer term and potential to have a negative effect on how the lives of disabled people are valued in society.
 - *“I think it would change a shift and ... what happens if one of the doctors or someone outside or anyone would say, “Why don’t you just go?”. The option is there. They all want to see me dead.”*

Key discussion themes

22. In addition to feedback that was either directly supportive of, or directly opposed to 'Route 2' (as set out above), there was further feedback on assisted dying in general, and feedback specifically focused on 'Route 2'. This feedback has been clustered into 6 key themes:
- a. autonomy of choice, dignity and peace of mind
 - b. assessing suffering
 - c. concerns around pressure and coercion
 - d. impact on family/loved ones
 - e. impact on health care professionals and health services
 - f. perceptions of disability in Jersey
 - g. slippery slope – concerns over erosion of eligibility criteria and safeguards over time.
23. Some of the feedback closely reflected arguments presented in the wider ethical and moral debate on the issue. Other feedback focussed on the practicalities and implications of establishing 'Route 2' assisted dying in Jersey.
- a. Autonomy/choice, peace of mind and equality
24. Amongst those who were supportive of assisted dying, the benefits of 'Route 2', some echoed responses to the wider Phase 1 and Phase 2 consultation feedback – ie. 'Route 2' allows those with 'unbearable suffering' the autonomy and choice should they wish to have the option to end their suffering. Some participants expressed this as 'peace of mind' should their health conditions cause suffering that they find unbearable at some point in the future.
25. Amongst those opposed to assisted dying, some stated should not be for an individual to choose when they die, but rather a matter left to nature or God, dependent on their belief system.
26. Others felt that the inclusion of 'Route 2' was a matter of equality, why should a person with a disability not have the right to die, if they are suffering unbearably and are not terminally ill?

Sample of responses:

"I want a choice for me and my body. Why should that be different because I have a disability?"

*“If I’m in pain, incontinent and can’t eat, I don’t want to be sh*tting my pants day in, day out and it costs me £7k a month. Why shouldn’t I be able to choose to go and leave that money to my children to enjoy?”*

“I’m in my 80s and I’m fine, but who knows what is round the corner? I want to discuss this with my children, so they know in advance it’s something I may want in the future.”

“I’m quadriplegic and happy right now, I’m not suffering, but I don’t want to be an older person in my 80s and my condition worsens, I don’t want to be stuck in a home in that situation. So I would like Route 2 in place for my peace of mind, so I get choose, if the time came.”

“It’s playing God, it’s not for us to choose when the right time is to die.”

b. Assessing suffering

27. Many participants, including those supportive of ‘Route 2’ expressed concerns around the difficulty of assessing suffering, including the complexities of assessing suffering that is not physical pain, for example mental suffering and anguish. Other participants expressed concern over the fluctuation of suffering, and how a person’s response to, and possible acceptance of suffering, may change over time. This included concerns as to whether a 90-day minimum timeframe was sufficient. For some other participants, it was a much more straightforward matter - if someone expressed they were suffering unbearably and did not want to carry on living, that is sufficient justification for assisted dying.

Sample of responses:

“Suffering and pain – that’s a very individual, subjective quality – how can that be quantified?”

“Suffering fluctuates, people have good days and bad days and feelings change over time, particularly in the days, months and years after a diagnosis or life changing incident.”

“How do you differentiate between suffering and the impact of medication on how you feel?”

“Being recently diagnosed, feels like wearing a pair of new shoes. It takes time to wear in.”

“It’s a long-drawn out process, isn’t it too long for those who are suffering unbearably and want to end their life? We should trust them, it’s their suffering.”

c. Concerns around pressure and coercion

28. A number of participants expressed concern that pressure from others to request an assisted death would be more problematic for those under ‘Route 2’, where they were not at the end of life – i.e. there would more likely be instances where family members put pressure on the person to request assisted dying under ‘Route 2’ (whether for ‘altruistic’ purposes, i.e., a wish to alleviate their loved ones suffering, or for other purposes, such as the pressure and burden on them of supporting their loved one who is suffering). Other participants held a different view, believing that family members would be unwilling to ‘let their loved ones go’, in spite of their pain and suffering, if they were not terminally ill/ already at the end stage of life.
29. For some, there were concerns about pressure from professionals, but this was in the minority. Most had confidence and trusted in professionals who, even if they were stretched and overworked, would ‘do the right thing’ and not directly or indirectly pressure a person towards requesting assisted dying. Concerns around family members centred around finances and inheritance.
30. Others expressed concerns about the pressure a person might place on themselves, should the option of ‘Route 2’ is available - i.e., if the option is there, should I consider it?”

Sample of responses:

“We saw it during covid, doctors pressuring for DNRs [Do Not Resuscitate orders]”

“We have regulation and oversight, there’s a tiny minority of bad eggs like Shipman and Lucy [Letby], but they shouldn’t dictate the decisions we make. Most professionals are there to help and support us.”

“To me, the benefits outweigh the possible misuse of the system.”

“You see it all the time in the island, fallings out in families over money, this would come into play here.”

“I’ve had times I’ve tried to end it, if this option existed for me, I would have wanted to take it. But now it’s different, I don’t want to die. So that thought scares me, what I could have done.”

d. Impact on family and loved ones

31. Discussion around the potential impact of ‘Route 2’ on family and loved ones focused on two areas:

- the possible impact on loved ones’ wellbeing if a family member choose to end their life potentially years or decades early, regardless of whether or not the loved ones supported the person’s decision?
- concerns about feelings of being a ‘burden’ on loved ones. Some participants were of the view that feeling a burden was not a legitimate reason for requesting assisted dying, other participants, felt this was a natural and acceptable response (i.e. I feel a burden and I don’t want my family to have to deal with it) that related directly to suffering (i.e. “seeing my family struggle makes me suffer.”)

Sample of responses:

“What support would there be for the family? Even if they were supportive, they may well have feelings of guilt, it could impact on them enormously”

“I’ve been with close family members when they were dying, the pain they went through, I don’t want that for me, and I don’t want my children to have to watch me go through that.”

e. Impact on health care professionals and health services

32. Participants expressed views about the potential impact on health care professionals should 'Route 2' be introduced, including concerns for their wellbeing and workload. Other responses expressed apprehension that a person may request assisted dying, particularly under 'Route 2' due to a lack of current services, or, for example, extensive waiting lists for certain care and treatment options, including mental health services.

Sample of responses:

"I've certainly experienced doctors with 'compassion fatigue', the professionals involved would need to be in the right space mentally, to be involved. And to care."

"It's not their fault, they're overstretched, sometimes they don't listen"

"We're asking for someone else to kill somebody else. What support do they get?"

"My husband was in pain, and we had to fight for the care he needed to ease his suffering."

"There's so many things I need to go to the UK for with my health. If assisted dying is available in Jersey, that might be the easier option."

"Palliative care isn't just for the dying, so we need to be sure it's good enough here. The States do not fund palliative care properly in Jersey."

f. Perceptions of disability in Jersey

33. A minority of respondents held the view that the introduction of 'Route 2' would have a negative impact on societal views towards disability. Most respondents were of the view that 'ableism' already happens and the introduction of 'Route 2' would not significantly change things.

Sample of responses:

"Society has improved attitudes towards many things, I'm an optimist. Look how far we've come with LGBT rights and racial equality."

"Nationally the picture's improved – representation is important in terms of seeing disabled people on tv as presenters and in dramas"

“Some people will be of the view it’s better for me to have it [assisted dying], than for me to live the life I’m living.”

g. Slippery slope – concerns over erosion of eligibility criteria and safeguards over time

34. Most respondents who were opposed to assisted dying - and a number of those who supported assisted dying but did not support ‘Route 2’ - expressed concerns about the eligibility criteria expanding and the proposed safeguards eroding over time. Many cited the example of Canada where the eligibility criteria had expanded rapidly since legislation had been introduced.

Sample of responses:

“Once this comes in, safeguards will be eroded as it has in every other territory. It’s being eroded and eroded. [In Switzerland] You don’t have to have a terminal illness or pain and suffering. So the conditions keep changing.”

“It’s the thin end of the wedge, even ‘Route 1’, the edges will get blurred.”

Additional considerations if ‘Route 2’ introduced

35. Participants were asked what additional measures should be considered if ‘Route 2’ is introduced, with a view to ensuring that disabled islanders are supported through the process. The responses are summarised below.
36. Jersey Assisted Dying Service considerations:
- a. A requirement for good access to communication support (with certified interpreters, not relying on friends or family) and advocacy support throughout the process [Note: this is accounted for in current proposals]
 - b. Assisted dying practitioners should have additional communications training, for example use of ‘layman’s terms’ to be sure the person really understands what they are being told [Note: this is accounted for in current proposals]
37. Government / societal considerations:
- a. As a society, we need to get better about discussing dying in general.
 - b. There is a need for better support and awareness of disability in Jersey - during the implementation phase, Government should run a ‘sister campaign’ – supporting positive social perceptions towards disability.

- c. Government should ensure that all health and care services are well funded and well-staffed, especially anything that might support a person to ease their suffering.

Appendix 1: Discussion Guide

Participants to have been sent a copy of the 'Easy read' version of the proposals in advance of the session: [Government of Jersey Assisted Dying Consultation \[easy read\]](#)

Note:

This discussion guide will be used by the Government of Jersey officers and voluntary and community sector representatives (Enable/JET) to facilitate the small group discussion sessions and 1-2-1 interviews.

This guide outlines the proposed areas for discussion at each session, in order to ensure the conversation covers key areas of interest, rather than being used a verbatim script.

The flow and order of the discussion will be led by the participants, and the guide used only as a prompt, where topic areas have not been raised spontaneously by participants.

The level of complexity and detail of discussion will be adjusted dependent on the group dynamics and needs of individuals within the group.

Introductions & purpose of session (10 minutes)

- **Introduce**
 - Policy officer – explain is working with Minister to develop the proposals
 - Other attendees –Enable/ JET representative

- **Purpose of session** – talking to islanders with long-term health conditions, or disabilities as well as their carers and families and those representing disabled islanders about assisted dying, focusing specifically on some key parts of the eligibility criteria.

We have had previous assisted dying conversations with islanders with long-term health conditions and disabilities – some of you may have been involved – but we've organised this small group session so we can have an in-depth discussion about the proposed eligibility criteria.

This is important because we want to ensure Government understands your views.

In addition to this session we have:

- organised an open invitation session that any people with long term health conditions or disabilities can attend (in addition other public and health care providers sessions)
 - organised a number of other small group sessions with JET/Enable
- **Output:** A short report summarising feedback from this session and the ‘open invitation session’ will be produced and presented to the States Assembly to help inform their debate on Assisted Dying on 21 May.
 - During the debate, States Members will be asked to decide whether assisted dying should be introduced, and in what way. This will include whether to permit assisted dying only for those with terminal illness. Or to also allow it for those with an incurable physical condition that gives rise to unbearable suffering but who may not have a short life expectancy [will explain this in more detail shortly]
 - **I’ll ask you to share your first name, but all comments and views will be kept anonymous.**
 - **Introductions** – Go round the group, share name and what made you decide to attend the session today.
 - **We’ll be discussing a serious subject-** death and dying- if you feel uncomfortable at any time during the session, please do step out and either leave or re-join the session when you feel ready. If you would like to talk to someone after the session for wellbeing support Enable/ JET representative can signpost you to this.
 - **Etiquette** – We all have different views on this subject and that’s ok. It’s important we respect everyone’s views, even where they differ from our own. The purpose of this session is to explore your views on the subject, and the variation of views, we don’t need to agree on everything.

Background (10 minutes)

- **What is assisted dying?** – definition of assisted dying
- **Steps for introducing it in Jersey** – timeframe – debate on 21 May, then need to draft law. Wouldn’t come into force for 3+ years.
- **Brief overview of proposals** – to include Eligibility criteria, with focus on ‘Route 1’ and ‘Route 2’; Jersey Assisted Dying Service; role of professionals (including right to refuse); request, assessment and approval, delivery of an assisted death; oversight and regulation.

Engagement with subject to-date and general views on assisted dying (5-10 mins)

- Had you heard about what’s being proposed before today’s session? If so, where/when/what?

- Is it a topic you've discussed with others previously?
- Is it something you've seen in the news/ heard about elsewhere
 - Explore awareness of other jurisdictions, including proposals in Scotland/IOM etc.
- What are your initial thoughts about what's being proposed?
- Do you think Jersey should allow people to choose to have an assisted death?
- What do you think the benefits and risks may be?
 - Prompt, in terms of:
 - how Jersey is seen
 - end-of-life options
 - access to healthcare services

Initial thoughts on 'Route 1' (10 mins)

As we've discussed, the proposals currently provide for Route 1 and Route 2:

- What impact do you think introducing Route 1 – terminal illness will have on:
 - all islanders
 - disabled islanders? [open ended, no prompt]

Initial thoughts on 'Route 2' (15 mins)

- What impact do you think introducing Route 2 will have on:
 - all islanders
 - disabled islanders?
- What are the potential positive effects of introducing 'Route 2'?
- What are the potential negative effects of introducing 'Route 2'?

Ethical review findings on 'Route 2' proposals (15 mins)

Where topics have not already been raised spontaneously by participants, explore some of the arguments put forward in the Ethical review.

Explain to participants that these are some of the arguments put forward in the review – do they agree/disagree with the following statements?

NOTE: Points below are direct quotes or summarise points from the ethical review, the facilitators (GoJ policy officer, supported by Enable/JET) will adjust the language or re-phrase to ensure language is accessible, where appropriate.

[There will not be sufficient time to explore all arguments in every session, facilitator will select points based on flow of discussion/area of interest for participants]:

Arguments in favour of 'terminal illness' only

- Restricting to 'Route 1' provides acts as a safeguard against premature death (i.e., only for the 'already dying')
- Focusing on terminal illness aligns with practice worldwide, as most cases of AD involve terminal illness
 - e.g., 72% of assisted dying in the Netherlands is for terminal illness, even though 'unbearable suffering' criterion is permitted.
- AD was originally intended to facilitate an already approaching death and to provide some level of control over the timing and manner of one's death. Extending beyond this context is also "linguistically awkward", since it is arguably inaccurate and potentially misleading to refer to "assisted dying" when, absent the fatal intervention, the person in question is not actually dying.

Impact on health care professionals

- Introduction of AD, and specifically Route 2 could impact on doctor/patient relationship
 - there is an inherent power imbalance and relationship of trust and concern that the perception of health care providers would influence the self-perception of disabled persons about the desirability of death compared to continue living with a disability
- Introduction of Route 2 could impact negatively on healthcare professionals' views towards disability and conditions which result in unbearable suffering
- Doctors may be more willing to participate in AD if limited to terminal illness. There is evidence that some doctors are (or become) reluctant to engage in countries where the practice has expanded in scope (i.e., beyond terminal illness) and increased in incidence.
 - Restriction to terminal illness helps to limit the scope of assisted dying (and its potential ramifications) by drawing a clear "line in the sand", which may ease concerns that assisted dying is in tension with the traditional medical commitments to curing, healing and avoiding harm.
- Participating in assisted dying may also place a psychological burden on health care professionals so restriction to terminal illness helps limit the incidence and thereby any psychological impacts.

Rights for those experiencing unbearable suffering [who don't meet 'Route 1' criteria]

- Limiting to terminal illness inconsistently and unfairly excludes others who are experiencing unbearable suffering .
 - A legal formulation of this argument holds that it is discriminatory to allow persons with terminal illness to obtain relief of suffering via

AD while prohibiting this for persons with illnesses or disabilities that are not terminal (or not within the specified timeframe)

- Allowing AD as a response to unbearable suffering respects the autonomy (self-determination) of those patients who wish to decide for themselves whether their life is no longer of the quality that merits continued living or whether their suffering is so serious that it is no longer tolerable.

Impact on societal views towards disability and suffering/ ableism

- Concerns that introduction of ‘Route 2’ may, over time, result in a change in societal attitudes towards older people, people with disabilities and long-term health conditions, in terms of valuing their lives and contributions towards society and/ or perceptions of quality of life.
- The ‘disability paradox’ refers to the gap between the negative perceptions of life with disability held by non-disabled people and the more positive perceptions held by people with disabilities themselves – this could intensify with introduction of ‘Route 2’.
- Allowing AD as a response to unbearable suffering makes (and reinforces) an “ableist” judgment about the negative value of the lives of people with disabilities. According to a broad definition of disability, all persons applying for AD on the basis of an incurable physical condition can be defined as disabled.
 - Allowing AD on such a basis creates a societally endorsed and medicalised ending-of-life for disabled persons who are otherwise not dying, thereby signalling that a life with disability is less worth living, and/or more intolerable, than a life without a disability.
 - This signal runs counter to the emphasis on universal design, ensuring universal access to goods and services, and efforts to create norms and standards that do not disadvantage disabled persons.

Impact on loved ones

- Allowing AD as a response to unbearable suffering offers a humane means of dying to people who might otherwise be inclined to end their lives via suicide, potentially in violent circumstances, and potentially with attendant trauma for family members and others
- family members may also be traumatised when someone close to them, who potentially has years to live, opts to receive AD under ‘Route 2’
- The statement: [borrowed from Dutch ethicist Boer] Route 1 allows “euthanasia to prevent a terrible death”, while Route 2 allows “euthanasia to prevent a terrible life”

Subjective nature of suffering

- Suffering is too vague, too multifaceted, and too subjective to be a useful or reliable eligibility criterion

- The perceived intolerability of suffering can change over time and be influenced by social and psychological factors (e.g., failures in social and disability support, wait times for care, intersecting mental health issues)
 - *in a recent study which followed patients with spinal cord injury, more than half of the patients reported suicidal ideation during the first two years. None of them thought they would have been able to make a truly informed decision in the early years following their injury, and none still wanted assisted dying after their adjustment.*

Other impacts of introduction assisted dying and 'Route 2' proposals (5 minutes)

- Are there any other ways you think Route 2 could have an impact on your life/ lives of disabled people in Jersey?

Support for disabled islanders (5 minutes)

[This section will need to reflect previous discussion/level of concern re introduction of 'Route 2']

- If 'Route 2' is introduced, what needs to be done to support disabled islanders who may request an assisted death?
- Prompt in terms of:
 - Awareness/information on assisted dying
 - Accessible information on assisted dying (BSL, easy read etc.)

Additional support during request and assessment process
- What other additional support should be considered for disabled islanders who are considering assisted dying?
- Prompt on:
 - Communication support/interpreting
 - Advocacy support
 - Wellbeing support

Safeguarding disabled islanders (10 minutes)

[This section will need to reflect previous discussion/level of concern re introduction of 'Route 2']

- If 'Route 2' is introduced, what needs to be done to ensure disabled islanders are not pressured into an assisted death?
- If appropriate, moderator to note existing safeguards within proposals, including:
 - Mandatory training for AS practitioners
 - 2 doctor approval, with supporting assessments/opinions
 - Multidisciplinary team, including social workers
 - Involvement of family in assessment process (with consent)
 - Wellbeing support for person and family members
 - Tribunal
 - Appeals process

Societal attitudes towards disability and long-term conditions (10 minutes)

[*This section will need to reflect previous discussion/level of concern re introduction of 'Route 2'*]

- If 'Route 2' is introduced, what needs to be done to support disabled islanders?
- Prompt in terms of:
 - Public information/campaign re people with disabilities
 - Specific to AD
 - General awareness
 - Training / info for professionals (available to all health and care professionals, in addition to AD practitioner specific training)
 - Appropriate conversations around AD
 - Perceptions of disability and 'ableism'

Other thoughts on the wider proposals (5 minutes)

- Do you have any thoughts on the proposals more widely?
- What are your concerns and/or hopes?
- What are the potential positives/negatives of assisted dying being available in Jersey?

Wind-up/close session (5 minutes)

- Is there anything else you would like to share today?
- Thank you for your time. It is greatly appreciated
- Remind participants of next steps (feedback report to be published)
- Remind participants that they can speak with Enable/JET representative with any other thoughts and to signpost them to wellbeing support.