

Meeting of the Cross-Party Group in the Scottish Parliament on End-of-Life Choices

Tuesday 25th January 2022
at 18:00
Online, via Zoom.

Scottish Parliament Headquarters
Holyrood, Edinburgh EH99 1SP

AGENDA

1 Welcome, introductions and apologies

Attendees: Rona Mackay MSP, Rachael Hamilton MSP, Liam McArthur MSP, Jackson Carlaw MSP, Elena Whitham MSP, Douglas Lumsden MSP, Liam Kerr MSP

Non-MSP attendees

Dr Sorcha Hume, Mark Hazelwood, Dr Hugh Wynne, Marcos Neves, Peter Cramond, Julie Lang, Gareth Morgan, Amanda Ward, Gordon Drummond, Ben Colburn, Tish Chalmers, Silvan Lulley, Harry McQuillan, Stacey Adam, Alastair Moodie, Chris Doye, Bob Keim, Moira Mather, George Lewes, Tom Shakespeare, Moira Symons, Scott McMurray, Alyson Thomson, Dovydas Kuliesas, Jo Ramsey, Serge Madrigal

Apologies from Ariane Burgess MSP

2 Minutes of previous meeting (Tuesday 28th September 2021)

Rona Mackay MSP welcomed all to the meeting of the CPG on End-of-Life Choices and asked if anyone proposed any changes to the minutes of the previous meeting. The minutes were agreed in full. Proposed by Elena Whitham MSP and seconded by Hugh Wynne.

3 Matters arising

Assisted Dying for Terminally Ill Adults (Scotland) Bill

Liam McArthur MSP shared the following key points

- High level of engagement on consultation, currently undergoing validation, response confirms public support of the law.
- First objective accomplished. Data provides enough scope for issues to be flagged. There will be further opportunities to fine tune as more data is processed.
- Unable to provide numbers and timeframe at this point - it will take time.
- Before the end of the year, we hope to be at parliamentary committee scrutiny stage
- Protecting the integrity of the process is important so we can't jump to any conclusions
- Medical aspect is one of the areas of most concern (for parliamentary debate).

Rachel Hamilton MSP: Question to Liam McArthur MSP

Requests chronological order, summary of where we are.

Mr McArthur's response

At this point there's a reluctance to talk about when a report would be available, as we are unsure about how long it will take to process the high volume of responses. As soon as we're at a point where there's a degree of reliability on the data processed, we will share this with the steering group of MSPs and others (mid-February estimate).

Stacey Adam comment to Mr McArthur

Indicates frustration with the people who are overly negative / confrontational.

Mr McArthur's response

We need to engage with legitimate complaints, some of them are coming from a genuine place, although not a lot can't be done in terms of framing of the bill. Allowing some of the debate and providing an opportunity for those issues to be recognised is important.

Harry McQuillan comment to Mr McArthur

Terminology is important, we must make sure it's on point.

Hugh Wynne question to Mr McArthur

Why is it that the bill seeks to exclude those who don't live in Scotland / is limited in scope.

Mr McArthur's response

We will have to deal with pressure from both sides. We can't continue to outsource the problem. I am happy to engage with the issue on balance.

4 Presentations and Discussion**Professor Tom Shakespeare****Key points**

- In their ordinary life many disabled people support assisted dying, as it enables disabled people to have control over their life
- Choices and rights, we want to have more control
- The only area where choice is not always supported (by disabled right groups) is assisted dying
- There's no evidence in jurisdictions that allow for assisted dying that people are facing pressures
- It's a good bill
- Not about turning doctors into people who end people's lives, they can only prescribe the medication, but the dying person must administer.
- Doctors are making sure nothing goes wrong
- People on ventilators, dialysis etc, can opt to discontinue treatment that will delay their death, there's an inconsistency.
- If you are dependent on medical technology, you are allowed to opt out.
- Pain relief doesn't eliminate all pain. People want to have dignity in their death.

- Assisted dying an insurance policy. The vast majority of people will not opt for it, but it's great to have it, providing comfort and peace of mind.
- There's a distinction between the end of life and end of suffering
- (The law would) give people control over death that is coming soon.
- It's been endlessly debated.
- I don't think disability rights groups should oppose it. It's not a threat, it's about people who are going to die imminently and providing a choice to do so on their terms.

Professor Ben Colburn

Key points

Disability-based arguments against assisted dying is going to be one of the central battlegrounds where people will show important reluctance.

Findings from recent research:

Three key myths

Attitudes of people with disabilities on assisted dying (AD) are always negative.

- Rebuttal: A high proportion of people with disabilities support AD, most disability rights organisations are either silent (88%) or openly neutral, only around 4% are openly opposed.

AD laws harm people with disabilities? People worry about slippery slope.

- Rebuttal: The fear is not in itself evidence that it's true
- Evidence of places where it's legal is reassuring
- There have been 3 systematic reviews on AD, they all looked for evidence of harm to people with disabilities. No evidence for slippery slope was found.
- Usually the least vulnerable, wealthier and more educated are opting for AD in larger numbers.
- A lot of data on AD from Oregon: vulnerable people are underrepresented in AD numbers. After decades of data, there's no correlation between AD and higher number of deaths in people with disabilities. This is especially significant because Oregon's model is the closest to the one proposed in Scotland.
- In the Netherlands, where legislation is more permissive, people aren't dying in bigger numbers than otherwise would, they're just having more choices when death is at the door.
- A study on people with mental disabilities who couldn't communicate was carried out in Holland and Switzerland, highlighting the importance of robust safeguards.

AD laws disrespect disabled lives

- Rebuttal: The focus of this proposed legislation is on terminal illness, most people with disabilities don't qualify. It also undermines the argument that AD laws make disabled lives look as if less they are worth living.
- Prohibition is the stance which shows disrespect, denying people with disabilities the right to exercise autonomy over their own lives and death, says

powerfully damaging things about the disabled, their abilities and their need to be protected.

- Empowerment and autonomy is consistent with the core of disability rights movements, the legislative process should listen to individual voices rather than just advocacy groups, we must create conditions where everyone can act consistently with their views.

Elena Whitham MSP question to both speakers

How did other countries (where legislation has passed) deal with these types of advocacy/lobbying groups?

Tom Shakespeare answered:

10 years in, Oregon disability rights organisations have changed their opposition stance based on the results.

Rona Mackay adds:

The word terminally ill must be drilled and plastered everywhere.

Liam McArthur adds:

On a constituency basis, engaging with individual voices is something we all ought to be doing. We need to bring in more neutral organisations and advocacy groups so the discussion isn't dominated by strong opposition.

Dovydas Kuliesas question to both speakers

What safeguards and assurances could be provided other than the scope of the bill?

Professor Colburn's response

There have been concerns whether people with severe communicative difficulties had been able to show consent. The evidence isn't relevant to our argument. There isn't reason to believe they were terminally ill. The importance of establishing consent is crucial: make sure it is indeed assisted dying, presence of a cooling off period, and it's only available for terminally ill people.

Rona Mackay MSP question to both speakers

Will religious opposition be as strong or stronger than previously?

Professor Shakespeare's response

It shouldn't be incompatible (religious faith and AD) as we aren't bringing death where it otherwise wouldn't have happened. Relief of suffering is at the core.

Professor Colburn's response

A lot of Christians would like to highlight the importance of compassion. About the slippery slope & worry about widening the scope, we have to trust our own parliament with its intentions, in terms of a sense of a strong boundary (i.e. eligible categories). It is very difficult to defend against straw man arguments. What underpins the language is genuine fear, however. What we say to that is; it's not inevitable (that the law would be widened), in places where it has happened (widening of situations allowing for AD), it's had to do with the public requesting it based on experience.

Hugh Wynne question to both speakers

Why is it that advocacy groups appear to be acting against choice? If we knew more about it we could counter it more effectively.

Professor Shakespeare's response

We are proposing legislation that allows for AD for people nearing death vs people who are simply suffering. Our bill isn't about suffering, it's about people dying. The suffering element is not on the bill.

Julie Lang comment

Anything that threatens the natural cycle of life (as with termination of pregnancy) is abhorrent to many West of Scotland Roman Catholics. The church hierarchy will exert huge pressure. We ignore that pressure at our peril.

Mr McArthur's response

For some of the reasons the speakers have touched upon, that influence and pressure can be a bit diluted. Among all faiths there is a variety of views. People might think their religious leaders don't represent them. I hope that a wider variety of views within these communities is represented, for example the medical community as evidenced by the BMA's recent change to a neutral position on AD.

Professor Colburn's question to Professor Shakespeare.

How about the argument: in principle I'm in favour, but it would be catastrophic to bring it in before we fix the issue of inequality of the disabled.

Professor Shakespeare's response

Some injustices existing can't be a block to other liberalisation. If we could only have this legislation when everything is perfect, it will never happen.

Silvan Lulley comment

If you reach your goal, you reach the goal of Dignitas; that no one has to come from Scotland to Switzerland to end their life.

7 Any other competent business

Nothing raised.

8 Date of next meeting

Tuesday 26th April 2022 at 6pm on Zoom.