# SPICe The Information Centre An t-Ionad Fiosrachaidh

# Assisted Dying for Terminally III Adults (Scotland) Bill – Detailed Call for Views Analysis

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# INTRODUCTION

The Health, Social Care and Sport Committee issued two calls for views which were open for submissions between Friday 7 June and Friday 16 August 2024:

- A short call for views for people who wished to express general opinions about the Bill as a whole.
- A detailed call for views for people, groups, bodies or organisations who wished to comment on specific aspects of the Bill.

The Committee received 13,821 responses to the short call for views and 7,236 responses to the detailed call for views.

Respondents were asked if they were answering on behalf of an organisation or as an individual. Of those who answered, the following responses were received from each:

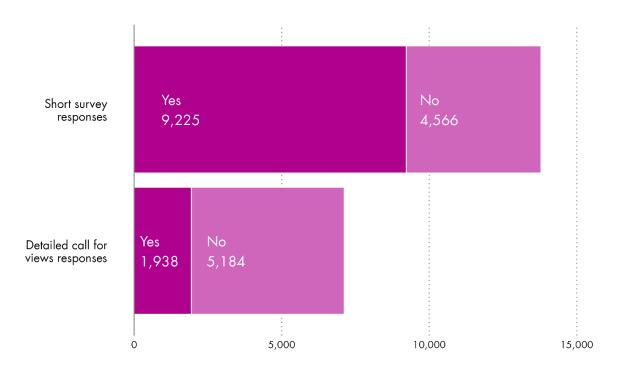
Table 1: Type of response to each	call for views <sup>1</sup>
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	Individual	Organisation	Total
Short call for views	13,791	30	13,821
Detailed call for views	7,122	114	7,236
Total	20,913	144	21,057

Individual respondents were also asked whether they lived in Scotland or not. The location of respondents who answered this question is shown in figure 1 for both calls for views.

<sup>&</sup>lt;sup>1</sup> Please note there may be some element of double counting as respondents were free to answer both calls for views.

# Figure 1: Do you live in Scotland?



We analysed overall support/opposition for the Bill broken down by residency, to see if there was any difference in opinion.

# Table 2: Opinion on the Bill broken down by residency – respondents to the <u>short</u> call for views

	Lives in Scotland (n=9221)	Not in Scotland (n=4564)
Strongly oppose	2,264 (24.5%)	1,167 (25.5%)
Partially oppose	67 (0.7%)	10 (0.2%)
Neutral/Don't know	28 (0.3%)	8 (0.2%)
Partially support	169 (1.8%)	83 (1.8%)
Fully Support	6,682 (72.4%)	3,296 (72.2%)
Not answered	1	-

# Table 3: Opinion on the Bill broken down by residency – respondents to the <u>detailed</u> call for views

	Lives in Scotland (n=1949) <sup>2</sup>	Not in Scotland (n=5193)
Strongly oppose	1,738 (89.1%)	4,897 (94.3%)
Partially oppose	22 (1.1%)	29 (0.6%)
Neutral/Don't know	16 (0.8%)	12 (0.2%)
Partially support	29 (1.5%)	29 (0.6%)
Fully Support	144 (7.4%)	226 (4.3%)

<sup>2</sup> This table was adjusted on 19 November 2024 to correct a minor error in which one submission that was strongly opposed to the Bill was initially counted as strongly supportive.

The tables show little difference in opinion between those resident in Scotland and those not.

However, there was a more obvious difference in opinion between the short call for views and the detailed call for views.

The short call for views was dominated by those in favour of the Bill and the detailed call for views was dominated by those opposed to the Bill.

There was strong evidence to suggest that a significant number of individual responses to both calls for views were the result of organised campaigns.

This illustrates the importance of not drawing conclusions about the balance of public opinion from this exercise. This is because respondents were entirely self-selecting and cannot be considered representative of the Scottish public.

The qualitative analysis does not exclude the views of people outwith Scotland. This is because we are interested in understanding the reasons underlying people's opinions on assisted dying, as well as gathering comments and concerns on specific provisions within the Bill.

# SUMMARY OF RESULTS TO QUESTION 1 IN BOTH CALLS FOR VIEWS

The first question was the same in both the short and detailed call for views and asked for the person's overall opinion on the Bill. The results for each call for views and a combined summary are shown in table 4.

Please note that there was nothing to prevent the same individual from completing both forms so there may be some element of double counting when looking at the combined results.

Throughout the process, it was made clear to respondents that the purpose of the calls for views was not to measure levels of public support for or opposition to assisted dying and/or the Bill, but rather to inform the Committee's scrutiny of the Bill at Stage 1 by offering a snapshot of respondents' experiences, opinions, questions, comments and concerns about the Bill.

Additional information provided to respondents before completing their response concluded: "The Committee will base any assessment of public opinion on published data from opinion polls. As responses to this call for evidence will be self-selecting, they cannot be assumed to be representative of public opinion and will not be treated as such."

For those wishing to understand more about public opinion on assisted dying, further information is publicly available on the results of polls conducted by reputable polling companies. As an example, see the <u>YouGov tracker on assisted dying</u>.

Table 4: Responses to the question 'Which of the following best reflects your views on the Bill?' – Breakdown of responses for each call for views and combined results

	Short call for views	Detailed call for views <sup>3</sup>	Combined
Strongly oppose	3,448	6,673	10,121
Partially oppose	78	55	133
Neutral/Don't Know	39	58	97
Partially support	263	63	326
Fully support	9,992	387	10,379
Total	13,820*	7,236	21,056

\*One respondent did not answer this question.

As can be seen from the table above, a majority of responses to the short call for views (74%) expressed support for the Bill, while the majority of responses to the detailed call for views (93%) expressed opposition to the Bill. Taking the two together, just over half of responses (51%) supported the Bill and just under half (49%) opposed it.

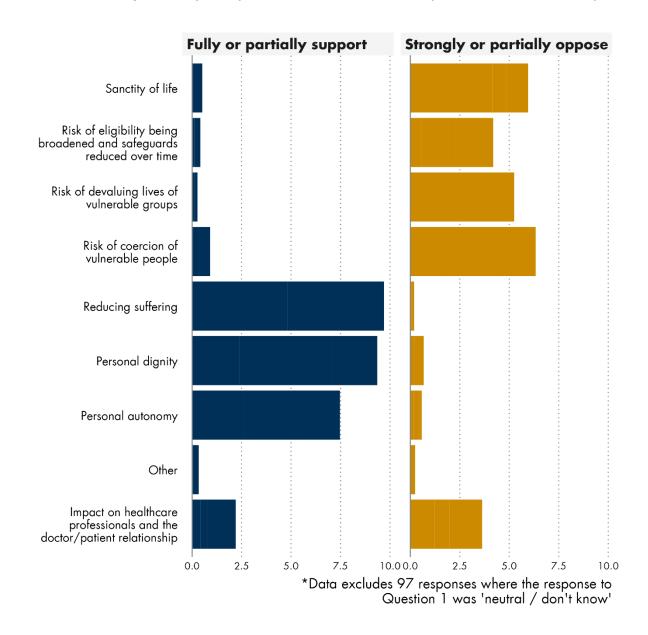
There is strong evidence to suggest that a significant number of individual responses to both calls for views were the result of organised campaigns.

Respondents to both the short survey and the detailed call for views were then asked to rank the three most important factors influencing their overall view of the Bill (support / neutral / oppose).

Figure 2 provides an overview of responses to this question, broken down in accordance with whether the respondent was supportive of / opposed to the Bill. Please note that, for the purpose of Figure 2, all rankings (whether 1st, 2nd or 3rd) are treated alike.

<sup>&</sup>lt;sup>3</sup> This table was adjusted on 19 November 2024 to correct a minor error in which one submission that was strongly opposed to the Bill was initially counted as strongly supportive.

Figure 2: Which of the following factors are most important to you when considering the issue of assisted dying? Please rank a maximum of 3 options. Number of responses ('000s) that ranked each factor (whether 1<sup>st</sup>, 2<sup>nd</sup> or 3<sup>rd</sup>)



The remainder of this paper shows the results from the detailed call for views. This was designed to elicit the views of people on some of the specific provisions of the Bill.

A separate analysis of the short call for views is available on the Committee webpage.

# ANALYSIS OF THE DETAILED CALL FOR VIEWS

# **QUESTION 2: ELIGIBILITY**

The Bill defines someone as terminally ill if they 'have an advanced and progressive disease, illness or condition from which they are unable to recover and that can reasonably be expected to cause their premature death'.

An adult is defined as someone aged 16 or over. To be eligible a person would also need to have been resident in Scotland for at least 12 months and be registered with a GP practice.

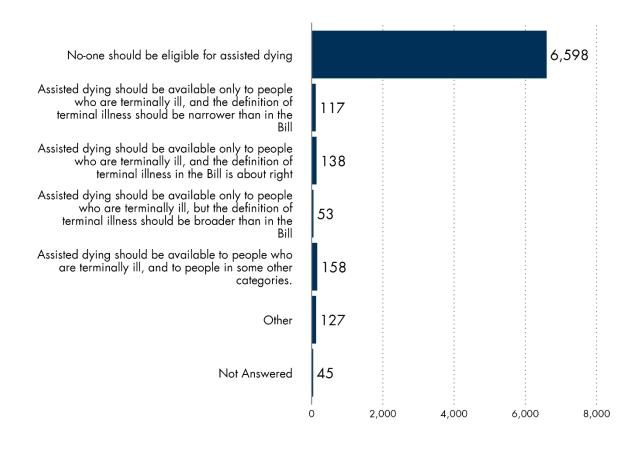
Respondents were asked for their opinions on assisted dying being restricted to those with a terminal illness, as well as the age criteria of 16 years.

# A. TERMINAL ILLNESS

Figure 3 shows a breakdown of opinion on eligibility being restricted to those with a terminal illness.

Because the majority of those who responded to the detailed call for views were opposed to the Bill, a large proportion of the responses did not address the detail of the Bill's provisions. Instead, they simply expressed their opposition to assisted dying in principle.

# Figure 3: Responses to the question 'Which of the following most closely matches your opinion on the terminal illness criterion for determining eligibility for assisted dying?'



As can be seen from the chart above, the majority of those who answered this question thought no one should be eligible for assisted dying.

Of the other responses, a combined total of 211 wanted some kind of extension to the eligibility. 117 wanted it narrowed and 138 thought it was about right.

Of the 127 respondents that chose 'other', suggestions could be summarised as follows:

## Extend or change eligibility beyond terminal illness

Several respondents made suggestions as to how the eligibility could be extended or changed. These suggestions ranged from extending eligibility to those with unbearable suffering, to being available to all mentally competent people as a matter of personal choice ('right to die').

Some highlighted that if the purpose of the Bill is to ease unbearable suffering, then this is not limited to people with a terminal illness. Other responses called for specific conditions to be included, such as:

- Motor Neurone Disease,
- Multiple Sclerosis
- Alzheimer's disease
- Chronic pain
- Locked-in syndrome
- Brain injury
- Mental illness
- Neurological conditions, including those that cause complete paralysis.

One response thought that quality of life should be the discerning factor as to whether someone qualified for assisted dying.

## **Prognostic timescales**

One of the more commonly suggested changes to the eligibility was that the terminal illness definition should include a reference to life expectancy.

These responses tended to think that 'reasonably expected' is too vague and subjective, and that there should be a specific time-period on the face of the Bill. Some examples included death expected within 6 or 12 months. One person called for the definition to be linked to the social security definition of terminal illness.<sup>4</sup>

However, others believed estimates of life-expectancy, and even whether an illness is terminal at all, are unreliable judgements and death is never guaranteed.

Others likened the lack of timescales and the reference to a 'reasonably foreseeable' death as similar to Canada and expressed concern that it would be open to loose interpretation.

# **Greater clarity**

Many respondents who chose 'other' did not suggest a change to the eligibility beyond terminal illness. Instead, they called for greater clarity on the current definition of terminal illness within the Bill.

There was a general feeling amongst these respondents that the definition is currently too vague, imprecise and lacked clarity. Some thought this would lead to inconsistencies in how it is applied.

Some highlighted that it is inconsistent with proposals in other UK jurisdictions.

## **Additional comments**

All respondents were given the option to provide additional explanatory text to their answer. Many of these simply restated their opposition to the Bill or repeated other arguments. Of those that specifically mentioned the terminal illness criterion, the main themes reiterated those detailed above. Those in opposition to the Bill tended

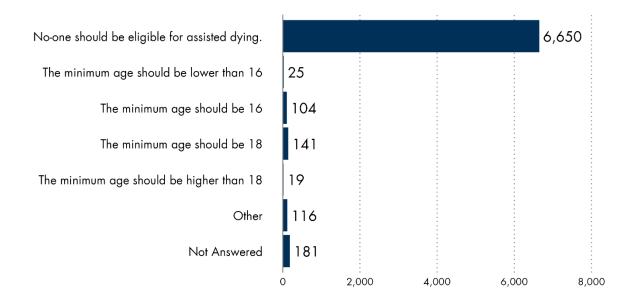
<sup>&</sup>lt;sup>4</sup> The person has an illness that, as a consequence of that condition, it is reasonably likely that their death could occur within 12 months.

to emphasise their opinion that the eligibility will inevitably broaden over time (i.e. "slippery slope" argument). This is discussed in the "Any other comments" section below.

# **B. AGE**

Figure 4 shows a breakdown of opinion on the minimum age a person would have to be to be eligible for assisted dying.

# Figure 4: Which of the following most closely matches your opinion on the minimum age at which people should be eligible for assisted dying?



As in previous questions, the majority of respondents to the detailed call for views thought no-one should be eligible for assisted dying and therefore they did not engage in the detail of this question.

However, of those who did, the largest proportion thought the minimum age should be 18. This was followed by those who selected 'other' (see analysis below), those who thought 16 was the right age, and then smaller numbers of those who thought it should be lower than 16, and those who thought it should be higher than 18.

Of the 116 people who chose 'other', some used this opportunity to reiterate their opposition to the Bill by saying no age is suitable. Other discernible themes are detailed below.

# Age should not be included in the criteria

The most common theme of those who suggested a change to the age, was that there should be no minimum (or maximum) age. The rationale commonly given was that terminal illness and suffering do not respect age limits. Instead, it was suggested that each case should be assessed individually within robust safeguards, regardless of age. Others highlighted the capacity of people younger than 16 and argued that eligibility should be based on individual competence.

# Suggested age thresholds

The other most common suggestion was for specific minimum ages other than 16. Suggestions ranged from 17, 20-25, 25+ and 65.

# **Additional Comments**

All respondents were given the option to provide additional explanatory text to their answer. Many of these simply restated their opposition to the Bill or repeated other arguments. Of those that did address the issue of age, the most common points made were:

# • 16-year-olds are not mature enough

Some respondents believed that young people are not mature enough to make such a decision. Arguments included that the human brain continues developing until a person is in their mid-20s, and that young people are impulsive and their emotions fluctuate:

"As a parent of teenagers, 16 is extremely young to make such a significant decision. We know that the teenage brain is developing rapidly and that the frontal cortex which controls reasoning is still developing. Adolescent emotions can be very intense and complex." (ANON-RS6Y-1XYP-6)

## • Consistency with other laws

Some respondents believed the age should be in line with other laws which define adulthood.

For some people this meant that 16 is the correct age but for others, 16 was felt to be too low and not in line with other age restricted laws. The most common examples given to illustrate this were being able to buy alcohol and tobacco:

"The age of 16 is incompatible with how we treat such young people when it comes to other decisions in life e.g. buying alcohol, voting etc. Society classifies such people as children and surely we can't expect those without life experience and maturity to be able to make such an irreversible decision." (ANON-RS6Y-1X9J-Z)

# • Age safeguards will disappear over time

In line with comments made about the definition of terminal illness, many opposed to the Bill claimed that any age limit within the Bill would be eroded over time. Some pointed to what has happened in the Netherlands and Belgium and expressed concern that it would eventually lead to the euthanasia of children.

# • Additional safeguards for young people

Some responses expressed a wish for additional safeguards for young people. Suggestions included:

- longer waiting periods,
- involvement of child psychiatrists,
- assessment for adolescent capacity.

Others also questioned the lack of involvement of parents and some suggested there should be a requirement for parents to be consulted and involved.

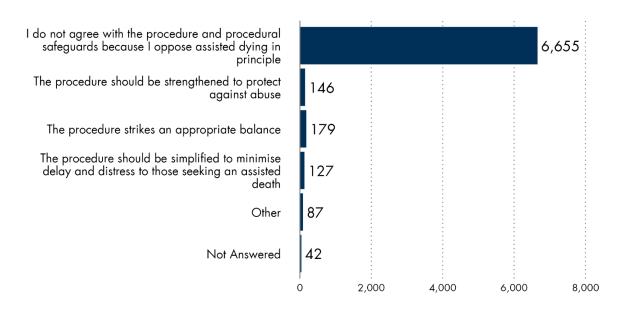
# **QUESTION 3 – PROCEDURE AND SAFEGUARDS**

The Bill describes the procedure which would be in place for those wishing to have an assisted death.

It sets out various procedural safeguards, including:

- examination by two doctors
- test of capacity
- test of non-coercion
- two-stage process with period for reflection

# Figure 5: Responses to the question 'Which of the following most closely matches your opinion on the Assisted Dying procedure and the procedural safeguards set out in the Bill?'



Again, the majority of respondents to the detailed call for views answered that they did not agree with assisted dying in principle.

Of those who answered 'other', suggested amendments to the process included:

- **Period of reflection** several respondents felt that the period of reflection set out in the Bill is too long. Some commented that it is unnecessary and cruel to make people wait when they are suffering. Others called for more discretion around the length of time and one person stated that evidence from the US showed a waiting period does not clarify decision making.
- **Tests of capacity** some respondents called for more in-depth, specialist assessments of capacity, for example, by independent psychiatrists.
- **Tests of coercion** some respondents asked for clarity on how coercion would be assessed and felt that the proposed process would not be able to pick up on more subtle forms of coercion.
- **Specialist service** some respondents thought such a service should be separate from the NHS and delivered by a specialist service. Some also thought it should not involve GPs. Reasons given for this included that GPs do not have the expertise or the in-depth knowledge of a patient's condition and background. Other reasons included GP workload and difficulties in getting appointments.
- **Counselling and therapy** some thought counselling and therapy should also be available/part of the process, and there should be a robust mental health assessment.
- **Involvement of others –** some responses suggested the involvement of others in the process. Suggestions included psychologists, lawyers and social workers. A couple of respondents also suggested that it should require legal approval, such as from a senior Court.
- **Appeals** some respondents thought that there should be an appeals process for both the patient and third parties such as family members.

# **Additional Comments**

All respondents were invited to provide additional comments on the procedure and safeguards. Many of these comments echoed what was said by those who chose to answer 'other' (detailed above). However, more detailed, general themes are outlined below.

## Prevention of abuse

Many respondents felt there is no way to completely protect against abuse.

"It is impossible to set out adequate safeguards against such a law being abused. Humans are desperately wicked - there is no way you could ever protect the vulnerable." (ANON-RS6Y-1X2Z-9)

These respondents frequently stated that the only way to safeguard against abuse is not to have assisted dying at all.

However, other respondents stated the safeguards within the Bill were similar to those in place in other countries and had been shown to be effective. For example:

"I have been practicing assisted dying since it became legal in my jurisdiction in 2016. I have overseen hundreds of assisted deaths at this point and I have literally never seen a patient coerced into an assisted death, nor have I been concerned that someone who may have not been eligible received access to an assisted death erroneously. The safeguards in our law (which closely resemble those in this bill) have been very effective at ensuring that only people who qualify for an assisted death and want one can access it." (ANON-RS6Y-1XN6-1)

# **Coercion and capacity**

One of the most common concerns expressed about the procedure and safeguards, was how to assess whether a person has been subject to coercion.

Generally, respondents expressing such concerns felt that coercion can be incredibly subtle and therefore difficult to pick up on. Sometimes these responses referred to internalised pressure, such as people not wanting to feel a burden.

Linked to this, others felt that existing systems in society may add their own pressure which they likened to a form of coercion. For example, inadequate palliative care and a lack of support to enable someone to have a decent quality of life. Some thought the option of assisted dying in itself applies a pressure as it implies certain people are a burden and their life is less valuable.

Many questioned whether an adequate test of coercion even existed and some simply thought it was not possible to know if a person had been coerced.

Similarly, questions were raised about capacity testing and who would be doing the capacity testing. Some felt that it would be beyond the capabilities of GPs and should be conducted by more specialist doctors.

"As a doctor who regularly carries out capacity assessments this is not a straight forward decision. Often patients have a degree of capacity and decline is often gradual over time. Just how you would be certain that coercion was not being applied to a patient I do not know. Such is the complexity of human interactions and relationships that it would be impossible to be certain." ANON-RS6Y-1XN5-Z

## Safeguards will be eroded over time

Many responses referred to other countries, most commonly Canada, and claimed that experience from these countries has shown that safeguards will be eroded over time.

Some likened the Bill's safeguards to those in the Abortion Act 1967 and argued that we now have 'abortion on demand' and the same will happen to assisted dying.

In contrast, a few felt the safeguards are in line with other countries and have been shown to work over time.

# **Period of Reflection**

In contrast to those who answered 'other' to this question and thought the period of reflection was too long, the remaining respondents (the vast majority of whom were opposed to assisted dying) were generally critical of the short length of the period of reflection. Most commonly, they believed it was too short to make such a grave decision and people may make mistakes in times of distress or change their minds if given longer.

## **Palliative Care**

The adequacy of palliative care was often raised, both in support and in opposition to the general principle of the Bill.

Many opposed to the Bill believed adequate palliative care negates the need for assisted dying.

For others though, there was a belief that no matter how good palliative care is, there will always be some people whom it cannot help. For these respondents, assisted dying was seen as a complement to palliative care rather than an alternative.

Others claimed that if safeguards are too stringent then people will attempt an unassisted suicide. Issues raised in relation to palliative care and suicide prevention are discussed in more detail below.

## Who should lead and be involved in the process

Some submissions thought that assisted dying should be led by a specialist service, rather than be subsumed within general NHS services. This is discussed in more detail in the '<u>Delivery of an assisted dying service</u>' section.

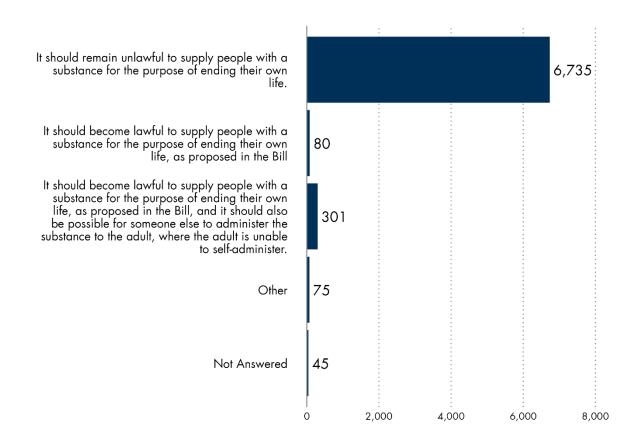
Alongside this was a belief among some that assisted dying should not be led by GPs. Reasons for this included that GPs have neither the expertise nor the resource to take forward such a service.

In addition, several respondents called for the involvement of other professionals in the process. Common suggestions included psychologists, lawyers and social workers.

# **QUESTION 4 – METHOD OF DYING**

The Bill authorises a medical practitioner or authorised health professional to provide an eligible adult who meets certain conditions with a substance with which the adult can end their own life.

# Figure 6: Responses to the question 'Which of the following most closely matches your opinion on this aspect of the Bill?'



The main themes to emerge from those who answered 'other' and the additional comments on the means of death are outlined below.

# **Quality of Death and Complications**

The most common theme to emerge from responses to this question were concerns about the drugs used in assisted dying and the impact they have on the quality of a person's death. These concerns were generally raised by those opposed to the Bill.

Commonly these submissions claimed there was evidence that the drugs used often result in a painful and/or prolonged death. Some claimed evidence from other jurisdictions shows complication rates ranging between 7-11%.

Often these assertions did not cite their sources but others referred to the annual reports provided by Oregon (which detail complication rates and time from ingestion to unconsciousness and death) as well as an article published in the <u>British Medical</u> <u>Bulletin</u>.

Conversely, individual respondents from New Zealand and Oregon claimed the drugs used have a good track record and few complications:

"Each medication method has a standard administration protocol to ensure consistent, safe and quality services. As of 31 March 2023, there have been no major complications related to the administration of the medication and all deaths have occurred within expected timeframes. The details of the protocol are only provided to practitioners involved in the assisted dying service." (Totara Hospice, New Zealand)

"I am a medical practitioner in the state of Oregon, USA, where we have a very similar law to this Bill in place for over 25 years. I have been both attending (prescribing) and consulting (second opinion) on more than 100 cases. The process and safeguards work well. The medications used are safe and effective, and complications extremely rare and even then (e.g. delayed time to death after unconsciousness) usually of no harm to the patient." (Dr Nicholas L Gideonse)

Some highlighted a lack of evidence around the drugs used in assisted dying and others questioned what testing there had been of such drugs. Some asked for a list of approved drugs to be published to enable proper scrutiny.

There were also questions about the role of the doctor if complications did occur, and what the law would permit them to do. For example, could they provide more medication or would they have to stand by?

# Method of Administration and Provision of Assistance

Many of those who responded to this question called for different options for administering a substance prescribed for an assisted death. These responses could be divided into:

- those who thought the person should have more options than just oral administration, for example, intravenous administration,
- those who thought the substance should be administered by a health professional, for example, by injection,
- those who thought there should be some kind of machine for administration which is still controlled by the individual.

Many of those who called for alternative administration methods argued that they would remove the physical barriers that may be faced by some people who want an assisted death. These respondents tended to believe that it would be unfair to deny the option of an assisted death to those who are physically impaired.

Some also argued that, with such barriers in place, people may choose to die earlier if they feared a time would come when they would be physically incapable of ingesting the substance.

Some responses highlighted that intravenous administration is available in other jurisdictions and is the preferred method chosen.

## **Role of the Doctor**

When speaking about the means of death, a significant number of responses mentioned the role of the doctor.

Many respondents were opposed to the involvement of doctors in the process at all, highlighting their duty to 'do no harm' and to preserve life. These respondents tended to be opposed to the Bill.

In contrast, some supporters of the Bill called for a greater role for doctors, such as administering the substance and being present throughout. These responses tended to emphasise the reassuring effect their presence would have, as well as the expertise they could bring to make sure people did not suffer.

Other comments included:

- The current law already allows for the doctrine of double effect<sup>5</sup>.
- Questions around what happens if someone changes their mind after taking the substance.

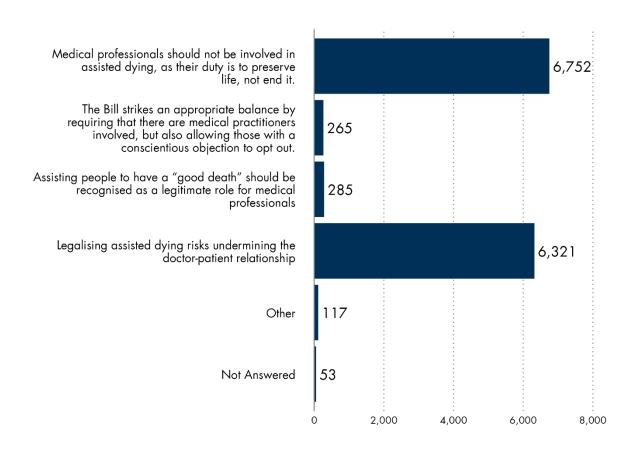
# **QUESTION 5 – HEALTH PROFESSIONALS**

The Bill requires the direct involvement of medical practitioners and authorised health professionals in the assisted dying process. It includes a provision allowing individuals to opt out as a matter of conscience.

Please note that for this question, respondents were allowed to select all responses that applied.

<sup>&</sup>lt;sup>5</sup> The principle that it is sometimes permissible to cause a harm in the pursuit of another good result. It is often used to refer to healthcare practices which seek to do one thing to relieve suffering but may also hasten death e.g. administration of high dose painkillers.

# Figure 7: Responses to the question 'Which of the following most closely matches your opinion on how the Bill may affect the medical profession? (Tick all that apply)'



Those who answered 'other' and the additional comments on this question were analysed for key themes. These are outlined below.

## The Duty of Doctors

The most common comment on this question was that the Bill would contradict the duty of medics to 'do no harm' and contravene the Hippocratic Oath. These comments came from those opposed to the Bill.

These respondents also argued that involving doctors in assisted dying would erode public trust and profoundly change the doctor/patient relationship.

Medical professionals have a duty to preserve life, I do not know any doctors personally who would partake in this killing. If my doctor did I would no longer trust him/her and in no way would go to that doctor therefore it is going to undermine the doctor/patient relationship. The whole medical profession will be undermined if this goes through. (ANON-RS6Y- 1XVQ-4)

Trust was described as being at the cornerstone of this relationship and some respondents felt that doctors can already provide support to someone to have a good death through palliative care. These responses often called for greater focus and funding to be given to palliative care.

Several respondents also claimed doctors themselves do not want assisted dying and highlighted reports that key medical organisations are opposed to a change in the law, for example, the Association of Palliative Medicine and the Royal College of General Practitioners.

Some were concerned that it would be used to save NHS resources, while others were fearful it could be used by individuals with sinister motives.

However, respondents in support of the Bill commented that providing a good death is consistent with a doctor's duties and having a comfortable death is part of modern medicine.

"Easing or ending prolonged suffering and pain, if it results in the death of the individual (as requested), should be seen as part of the medical professional's duty as the oath is to Do No Harm, and prolonging suffering could be viewed as Doing Harm. I see no glory in suffering, or in forcing a person to live in pain or distress if they wish to have their lives ended." (ANON-RS6Y-1X55-7)

Some also pointed out that – under the doctrine of double effect – doctors already administer medicines which may hasten death.

## **Conscientious Objection**

Among those who supported the Bill, there was general support for the conscientious objection clause. These respondents tended to feel that assisted death should only be provided by those who believe in it. Some also wanted assurance that it would apply to all health professionals involved, including nurses and pharmacists.

Some also stressed that, while they supported the conscientious objection clause, those opting out should not be able to obstruct those seeking an assisted death.

However, the conscientious objection clause was also raised by those opposed to the Bill. These responses expressed concern about the practical application of the clause and the pressure that will be placed on those who opt-out.

Some felt that a lack of resources and staffing could apply pressure on unwilling staff to take part, as opting out would increase the workload of their colleagues. Others claimed opting-out could jeopardise their careers and there will be peer pressure to participate.

The Royal College of General Practitioners (RCGP) backed calls from the British Medical Association to make it unlawful to discriminate against, or cause detriment to, any doctor on the basis of their refusal to participate in assisted dying.

Many submissions pointed to the experience of implementing the conscientious objection clause in the Abortion Act 1967 and argued that it would eventually be eroded and provide inadequate safeguards for professionals.

"Legal safeguards to protect the conscientious objections of medical professionals to assist in abortions have proved inadequate. The same will happen with this bill." (ANON-RS6Y-1311-T)

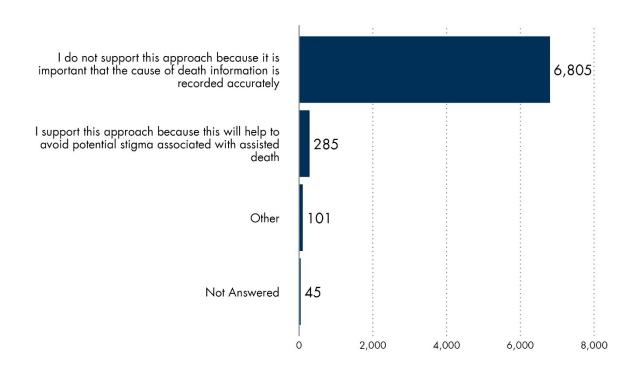
# **Psychological support**

Several respondents called for psychological support for staff involved in facilitating an assisted death. These responses were concerned about the negative impact assisting in deaths could have on the health and wellbeing of the professionals involved.

# **QUESTION 6 – DEATH CERTIFICATION**

Under the Bill, if a person underwent an assisted death, their underlying terminal illness would be recorded as the cause of death on their death certificate, rather than the substance they took to end their life.

# Figure 8: Responses to the question 'Which of the following most closely matches your opinion on recording the cause of death?'



The most common themes to emerge from those who chose 'other' and the additional comments on this question could be divided into:

- those who thought both reasons should be recorded on the death certificate,
- those who thought recording anything other than suicide would be inaccurate,
- those who thought the 'true' cause of death should be recorded.

Those who thought both the underlying illness and the assisted death should be recorded tended to be in support of the Bill.

In contrast, those opposed to the Bill felt strongly that recording the underlying illness would be lying and falsifying a public record.

NHS Education for Scotland (responsible for staff education in the NHS) noted that doctors are currently trained to put accurate information on the death certificate and expressed concern that not recording an assisted death would be contrary to this and out of step with the treatment of other sensitive death situations.

Many respondents also suggested that the 'true' cause of death should be recorded on the death certificate. However, there was a notable difference of opinion between supporters and opponents of the Bill in what would constitute the 'true' cause of death.

Those in support of the Bill felt that the terminal illness would be the main cause of death, while those opposed contended that suicide would be the main cause.

In relation to stigma, some in support of the Bill felt that there was nothing to be ashamed of and recording an assisted death may help to tackle any stigma.

"It is important that there is accurate evidence of the incidence of assisted dying. Not recording it on the death certificate could add to stigma by indicating that there is something shameful about the actual cause of death." (ANON-RS6Y-1X31-1)

In a similar vein, opponents to the Bill questioned why an assisted death would need to be covered up if there is nothing wrong with it. Some seen it as tantamount to acknowledging that it is morally wrong.

"The mention of potential stigma is indicative of a general public conscience that what is being [suggested] is morally wrong!" (ANON-RS6Y-1659-9)

# **QUESTION 7 – REPORTING AND REVIEW REQUIREMENTS**

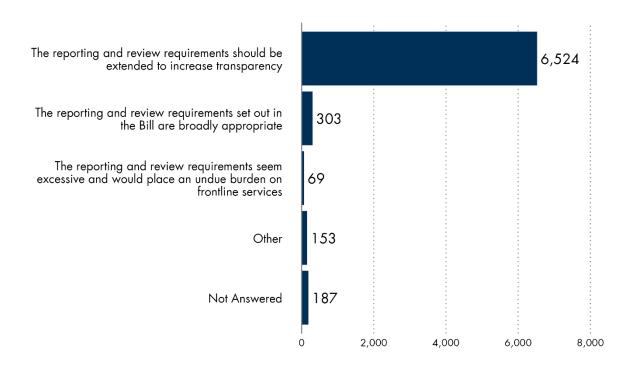
The Bill proposes that data on first and second declarations, and cancellations, will be recorded and form part of the person's medical record.

It also proposes that Public Health Scotland should collect data on: requests for assisted dying, how many people requesting assisted dying were eligible, how many were refused and why, how many did not proceed and why, and how many assisted deaths took place.

Public Health Scotland would have to report on this anonymised data annually and a report would be laid before the Scottish Parliament.

The Bill proposes that the Scottish Government must review the operation of the legislation within five years and lay a report before the Scottish Parliament within six months of the end of the review period.

# Figure 9: Which of the following most closely matches your opinion on the reporting and review requirements set out in the Bill?



Most of the comments on this part of the Bill simply expressed their opposition to assisted dying and stated no monitoring or reporting would be needed if the Bill is not passed. Other key themes are detailed below.

## Level and frequency of reporting

However, of those who did critique the provisions, a common opinion was the reporting and monitoring requirements should be as demanding, robust and transparent as possible. This was viewed as important to safeguard against coercion and abuse, as well as to build public confidence.

Several respondents thought that 5 years was too long for the review period and suggested shorter time periods. These ranged from 1 year to 3 years. Some people had concerns that the review may be used to usher in expansion to the legislation.

## Additions to reporting and monitoring

There were calls for the creation of an independent body to oversee the implementation of the Bill.

Some submissions also made suggestions for specific additions to the information that should be recorded, including:

- incidence of complications and adverse events,
- impact on staff and relatives,
- data on protected characteristics,
- socio-demographic information,
- data on who is involved in assisted dying and their qualifications,
- cases with psychiatric assessment,
- cost savings and expenses occurred,
- data on who is involved in assisted dying and their qualifications.

# ANY OTHER COMMENTS IN RELATION TO THE BILL

At the end of the survey, respondents had the opportunity to include any other comments they had on the Bill. People mainly took the opportunity to expand on their reasons for opposing or supporting the Bill; to provide additional comments to previous questions; or to raise issues not covered in the survey. Comments relating to previous questions in the survey were included in the analysis for each question above.

Note that the vast majority of respondents to the detailed call for views were strongly opposed to the Bill. The identification of themes and the summary of the sentiments expressed reflects this.

Comments are discussed in more detail under the following headings:

- reasons for opposing or supporting the Bill
- additional comments on the Bill.

# **REASONS FOR OPPOSING OR SUPPORTING THE BILL**

The vast majority of respondents to the detailed call for views strongly opposed the proposals in the Bill. Their reasons for doing so are discussed in the sections highlighted below, interspersed with comments from respondents who supported the Bill, where relevant. The key themes for those opposing the Bill were:

- the dangers of a "slippery slope" towards more expansive legislation
- that the proposal undermines the dignity, or sanctity, of life
- the potential impact on healthcare professionals
- the potential impact on healthcare services
- the potential impact on suicide prevention activities
- the potential impact on family and friends
- that alternatives primarily palliative care were available.

There were also comments from respondents who supported the Bill which did not fit into the themes highlighted above. These are discussed further in the section looking at "Reasons for supporting assisted dying legislation".

# THE DANGERS OF THE "SLIPPERY SLOPE" TOWARDS MORE EXPANSIVE LEGISLATION

# Summary

Common comments included that this was "a dangerous path to go down" and "the thin edge of the wedge". Broadly, comments discussed under this heading related to the fact that, while it may be argued that only a few people would access assisted dying, use would expand over time or criteria would be widened to include more categories of people. There were also concerns that, while the Bill would legislate for voluntary assisted suicide, this might be expanded in the future to cover action by doctors to directly end the lives of patients, potentially even without their consent.

## Eligibility criteria expanding over time

The provisions in the Bill as they stand would only apply to people who had a terminal illness. However, some respondents argued that many campaigners for assisted dying want more expansive legislation. Respondents expressed concerns that these campaigners would see this as a first step and push for criteria currently appearing in the Bill which restricted eligibility to be removed.

The Religion and Morals Committee of the Free Church of Scotland was among those to note that eligibility had expanded in other countries with assisted dying legislation. This was usually because of campaigning by supporters or because of interpretation of necessarily ambiguous wording.

Anscombe Bioethics suggested that, even if the law doesn't change, practice might. For instance, in the US state of Oregon, terminal illness is now defined in relation to treatment acceptable to the patient. Thus, someone could refuse treatment that others would find reasonable and meet the requirements for a terminal illness. They further noted that, even in jurisdictions where assisted dying has been an option for 20 years, the number of people accessing it continues to rise.

Issues with the definition of a terminal illness are discussed in more detail above. However, respondents argued that it was ambiguous, particularly without the inclusion of a specific timeframe when death could reasonably be expected. It was argued that a number of conditions could meet the requirements even when death was not expected soon. Some respondents suggested that guidance – from the Scottish Government or healthcare professionals' regulatory bodies – could allow expansion without oversight by the Scottish Parliament.

Totara Hospice supported the Bill and challenged this view. It stated that assisted dying laws had not been expanded in its base of New Zealand or in many other countries. It also argued that any expansion was in the hands of the democratic process.

DIGNITAS challenged the view that expansion was inappropriate. In its opinion, expansion was an appropriate response where society no longer agreed with the

barriers which were put in place to prevent some groups of people accessing assisted dying.

# The Scottish Parliament's role in future changes to the law

Cerebral Palsy Scotland was among those groups flagging that much in the Bill is left to regulation-making powers given to Scottish Ministers. In its view, it would therefore be possible for criteria to change without the scrutiny which accompanies primary legislation. The Church of Scotland called for guarantees in relation to the process to be followed if eligibility criteria in the Bill were to be reconsidered. The Bishop's Conference of Scotland noted that it was not possible to draft laws in a way which included legal protection from future expansion.

# Risk to disabled people

A number of respondents saw the potential future expansion of eligibility criteria as a significant threat to disabled people. It was strongly argued, especially by some organisations representing disabled people, that there were many barriers to disabled people living fulfilling lives at present. These barriers included general discrimination, access to appropriate care and support services and access to financial support.

Given the ongoing battles disabled people must fight to get their support needs met, it would be very easy to feel that life was not worth living and opt for assisted dying. Better Way highlighted the concerns of the UN Human Rights Special Rapporteurs in 2021:

"We all accept that it could never be a well-reasoned decision for a person belonging to any other protected group – be it a racial minority, gender or sexual minorities – to end their lives because they experience suffering on account of their status ... Disability should never be a ground or justification to end someone's life directly or indirectly."

Not Dead Yet UK argued that assisted dying should not be prioritised over solutions which would result in positive change for people with disabilities. One individual respondent referred to the "gas-lighting of disabled people who are made to feel selfish or a burden in asking for needs and rights to be met." (17S8-7)

## Another stated:

"Many disabled people fear that to show any signs of melancholy, struggle with their disability, or frustration with their suffering, would be to affirm a wish to die." (1XY1-7)

Glasgow Disability Alliance highlighted barriers to disabled people being able to register the level of protest they'd like against the Bill. These barriers included digital exclusion, support needs and health challenges – all of which made physical protest and engaging with consultations difficult.

# Moving from assisted suicide to euthanasia

Some respondents were also concerned that the law would be expanded to allow doctors to take a more direct role in ending the lives of their patients, potentially without their consent. There was a view that opening the door to assisted suicide could lead to voluntary or non-voluntary euthanasia by giving doctors a role in deciding when a patient's life was not worth living. As one individual respondent put it:

"I am deeply concerned that this will lead to the state deciding who is fit to live and who is not." (1JYW-Y)

Examples of the practice of non-voluntary euthanasia from countries where assisted dying was legal were given. This included the Netherlands, where the Groningen Protocol allows doctors to euthanise severely disabled babies.

## **Experience in other countries**

Many respondents highlighted experiences from other countries and regions where assisted dying was legal as evidence of the risk of expansion. As noted above, the Netherlands allows non-voluntary euthanasia in certain, limited circumstances. Both Belgium and the Netherlands have expanded their assisted dying regimes to include euthanasia requests from children (with age restrictions, or where they can understand the request).

Other countries have – or are considering – expanding eligibility criteria to include those with mental health conditions only, or to remove a requirement for illness to be terminal.

Canada was often cited as an example of a country where access to assisted dying (under their regime, this includes assisted suicide and administration by a doctor) was too broad. Examples of people who had a qualifying condition but were argued to have accessed assisted dying on grounds of lack of financial support or homelessness were given. One individual respondent highlighted the case of their father – who in their view had been able to access assisted dying despite a clear history of suicidal ideation.

Canada was also highlighted as an example of higher than expected use of assisted dying. Cases had continued to increase significantly year on year.

Oregon legalised assisted dying in 1997. Its experience has also been of increasing use, although not at the rate of Canada. However, respondents who opposed the Bill often highlighted the reasons why people access assisted dying in Oregon. State statistics show that, in recent years, more people have identified being a burden on others as a reason for accessing assisted dying than inadequate pain control.

# UNDERMINING THE VALUE, OR SANCTITY, OF LIFE

# Summary

There was concern that introducing assisted dying had ramifications well beyond those who might benefit from accessing this service. Many respondents thought that supporting the proposition that some lives were not worth living had serious consequences for how disabled people, older people, sick people and people with other vulnerabilities would be viewed by society.

There was also a view that some people would internalise these value judgements and consider themselves to have a duty to die to minimise the burden on their families, society or the NHS. This was best summed up in the comment "When does a right to die become a duty to die?"

## Sanctity of life

A large number of respondents had clear religious beliefs. Many challenged the approach in the Bill on the basis that life was God-given. In their view, life was God's to give and God's to take away.

Many respondents, from both the Christian and Muslim faiths, were clear that it would be against their religious principles to do anything for the deliberate purpose of quickening the end of someone's life. Some also highlighted their belief that anyone involved in this practice could go to Hell.

However, there were also respondents who did not consider assisted dying to be against their religious principles. The Scottish Christian Forum on Assisted Dying noted that, in practice, Christians have a wide range of views on this issue. Several members of the clergy gave accounts of changing their views from opposing to supporting assisted dying on the basis of the suffering they had seen at the end of life as a result of their positions.

The Religious Alliance for Dignity in Dying expressed the view that a loving God would support steps to end unnecessary pain, so that assisted dying, in strictly controlled circumstances, is compatible with religious belief. It said:

"Belief in the sanctity of life – in other words, how precious it is – does not mean believing in the sanctity of suffering or disregarding steps to avoid it. There is nothing holy about agony".

Other groups counselled against giving too much weight to religious views. Totara Hospice said:

"Faith and democracy do not make guaranteed bed fellows; democracy simply guarantees the right of faith to its own bed."

The National Secular Society highlighted its view that a number of religiouslymotivated bodies had moved to using more secular language to express their opposition to assisted dying. It said: "The religious views of some, however sincerely held, should not restrict the freedoms and choices of others."

#### Value of human life

Many respondents were concerned that the proposals devalued human life in general. The Christian Medical Foundation was of the view that legalising assisted dying would inevitably strengthen the perception that some lives were not worth living. Further, the costs of caring for people would be better redirected to more productive members of society.

The Scottish Council on Human Bioethics counselled against the risks of an approach which valued human life only because of its quality. This moved away from the current model of according all human lives equal value and risked undermining our concept of civilisation. They said:

"... it would give the message that the value of a human life is only based on subjective choices and decisions and whether this life meets certain quality standards."

An individual respondent argued that legalising assisted dying would affect society's attitudes to disability. If people could access assisted dying because of symptoms like pain, incontinence and dependence on others, "what does this mean for disabled people who resolve to live with these symptoms, not just for the final few months or year, but every day of their lives?" (1XY1-7)

Another individual respondent stated:

"As a chronically ill woman, it does not surprise me that able-bodied individuals are seeking to push this Bill. They are invalidating my lived experiences as "less than", that my existence is not worth living." (1JJB-U)

Some respondents discussed existing problematic use of DNR notices ("Do Not Resuscitate" or "Do Not Attempt Cardio-pulmonary Resuscitation") in health services. This was seen as demonstrating that dangerous judgements about the value of the lives of disabled people were already being made. The Neurological Alliance of Scotland was among those highlighting use of DNR notices, without consultation with patients and family, during the COVID pandemic.

## Fear of becoming a burden

The risk of pushing people towards a decision to access assisted dying because they didn't want to be a burden was highlighted as a risk by many respondents who opposed the Bill. Some considered it impossible to guard against this risk, because it was an internalised view of oneself. Risks highlighted included that people might access assisted dying because they felt a burden on loved ones, society or the NHS, or because they didn't want to see a potential inheritance spent on care costs. The Free Church response noted that, during the COVID pandemic, people had acted to protect the NHS by not using services. In their view:

"A similar desire not to be a burden to the NHS could lead to people choosing assisted suicide rather than treatment, and this is fundamentally wrong."

The Free Church of Scotland Presbytery of Inverness, Lochaber and Ross argued that accepting assisted dying would mean that patients would have to justify their ongoing existence to family and health services. The Royal College of Physicians of Edinburgh saw a risk that people with life-limiting illnesses or severe disabilities would be stigmatised if they did not opt for assisted dying. An individual psychiatrist respondent stated:

"In times where money and resources are limited, the pressure on people to speed up their death to avoid being a burden on the system must be a factor in the minds of those delivering and receiving care." (17DG-7)

## Autonomy

Some respondents who opposed the Bill attacked the idea of autonomy which they felt underpinned attitudes in support of the Bill. They argued that the idea of assisted dying puts the autonomy of the individual to choose to die over the safety of the majority, who may feel pressured or a burden as a result.

They believed that, for society, the safety of the majority was the most important factor. The Apostolic Church said:

"This is not a private matter up to individuals to decide what is right for them, because if we legalise suicide for some, it cheapens human life for all." (1XZX-F)

Some respondents could see the benefits to some people of assisted dying. There was specific acknowledgement of the suffering involved in conditions like Parkinson's. However, they nevertheless thought the risks to society more generally outweighed those benefits. As one individual respondent put it:

"The benefits to a few do not support the risk to the many people who will access this through coercion and lack of other options." (1KDC-Q)

Some respondents also saw a power disparity between those who advocated for assisted dying and those whom it might put at risk.

"There probably are a group of people who will gain from the reassurance of knowing they can end their lives. They're generally articulate and educated and they live lives where they are used to having power to make meaningful choices. There's also many people who're more marginalised and vulnerable." (1XVD-Q)

# POTENTIAL IMPACT ON HEALTHCARE PROFESSIONALS

# Summary

There were widespread concerns about the potential impact of the Bill on healthcare professionals. Key concerns were that it would undermine trust in healthcare staff; that it would place further strain – emotional and work-related – on healthcare staff; and that many healthcare staff were morally opposed to assisted dying and may leave their jobs as a result.

Many respondents who opposed the Bill made reference to the medical principle – from the Hippocratic Oath – to "do no harm". Their view was that breaching this principle was a risk to patients and could undermine the motivation of many healthcare staff for choosing their careers. The Bill contains a conscientious objection clause. Issues around this are discussed above. However, some respondents were concerned about how healthcare staff who conscientiously objected would be treated.

## Undermining public trust in healthcare staff

The risk that assisted dying would undermine trust in healthcare staff was a significant concern among respondents who opposed the Bill. Some were of the view that they could no longer trust doctors to defend their interests at a point when they were vulnerable. As one individual respondent said:

"How can we trust our GPs and health professionals to have our best interests at heart when they must by law offer death as a treatment option?" (1XM8-2)

## A former GP stated:

"I am very relieved that I have retired from active practice before this Bill has a chance of becoming law. I think it would hugely damage my relationship with vulnerable patients with life-threatening diseases, who have to be able to trust their doctor that he/she is offering the best possible care. I spent 40 years fighting for my patients to have access to the best available care, regardless of what they could afford, and am proud to have worked in a health service which generally delivered that." (1X9F-V)

An NHS psychotherapist who worked with suicidal people noted that their reactions to what their patients say are an important part of the process. They asked: "If their clinician doesn't value them, how can they hold on to or develop a sense of their own worth?" (1X6Y-C)

However, there were also comments from healthcare professionals who supported change. One former GP, who wanted to see assisted dying introduced, did not think it would affect the doctor-patient relationship "any more than it does with a Vet". (1XJG-E)

# Emotional toll on healthcare staff

Many respondents noted the psychological burden on healthcare staff of providing assisted dying. There was a fear that this could cause burn-out.

The Royal College of GPs discussed the issue of "moral distress" caused by conflicting emotions when dealing with a patient's request for assisted dying. It noted a lack of research on the emotional impact on clinicians for participating in assisted dying but highlighted that what is available suggests a significant impact.

The Royal College of GPs also noted that assisted dying was a complex service which would require time and sensitivity to deliver. It was concerned that its introduction would exacerbate existing pressures and workforce shortages. It stated:

"We have concerns that the model currently proposed for the legalisation of assisted dying in Scotland could have negative impacts on recruitment and retention of our healthcare workforce, and particularly of GPs."

## Opposition of some healthcare professionals to participating in assisted dying

Respondents highlighted that many healthcare staff were opposed to participating in assisted dying. For some, this was a moral objection, but it was also noted that it could be about the emotional burden, or the impact on other healthcare service users.

A number of healthcare professionals – GPs, hospital doctors, nurses and others – highlighted their personal concerns around, or objections to, the Bill. However, some practitioners from countries and states where assisted dying is legal expressed their support for assisted dying. One doctor stated:

"It is of tremendous value in relieving the suffering, both existential and physical, of terminal illness to have the option available." (1X6D-Q)

Respondents who opposed the Bill highlighted that those most involved in end of life care – practitioners of geriatric medicine and palliative care medicine, and GPs – were most likely to be opposed to assisted dying. Living Well and Dying Well suggested that resistance from those most likely to be involved in implementing assisted dying meant that consideration would have to be given to other models of delivery.

Better Way was among those quoting a survey of Scottish palliative care doctors from 2022. This highlighted that 75% of doctors would not be willing to participate in any part of an assisted dying process, with 43% saying they would resign if their organisation took part in assisted dying. An individual palliative care doctor noted that the actual numbers of doctors featured were small. However, "... there are more MSPs than palliative care consultants in Scotland." (1XZG-X)

The British Islamic Medical Association highlighted that 51% of its members agreed that the introduction of assisted dying would affect their career choices as doctors.

# Treatment of staff who conscientiously object

There was also concern for those who might choose to conscientiously object to participating in assisted dying. These included that conscientious objection would drive doctors away from the areas of practice most involved in end of life care or that staff may face difficulty pursing their chosen specialism if they exercised their right to conscientiously object.

An additional issue discussed by respondents was whether doctors, even those who conscientiously objected, would be required to raise assisted dying as an option for patients who might qualify. It was noted that, in Canada, doctors have a duty to inform qualifying patients what their system – Medical Assistance in Dying – is available. Court decisions<sup>6</sup> governing the discussions doctors must have with their patients to ensure informed consent in the UK require that all reasonable treatment options are discussed.

# POTENTIAL IMPACT ON HEALTHCARE SERVICES

# Summary

Respondents – including some who were neutral or supported the Bill – expressed a range of concerns around the impact of introducing assisted dying on healthcare services. A common view was that services were stretched enough and couldn't – or shouldn't have to – deal with the additional demands an assisted dying service would bring. The lack of clarity in the Bill about how an assisted dying service would be delivered was seen by some as making discussions about the impact of practical delivery more difficult. Another key concern was that it would create perverse incentives to save money.

# Exacerbating existing pressures on health services

The comments from the Royal College of GPs above highlight concerns about adding to the workloads of already stressed and over-stretched GPs. The Royal College of Nursing also argued that district nursing was under too much existing pressure to provide the time, care and respect those accessing assisted dying would deserve.

A number of individual healthcare professionals raised concerns about the impact of assisted dying on their workloads. Psychiatrists in particular – who may be called on to provide specialist reports on a patient's capacity to make a decision about assisted dying – were worried that they would not be able to respond in a timely manner.

Some respondents expressed the view that, even if specific funding was made available to deliver assisted dying, there simply weren't sufficient staff at present within NHS services.

<sup>&</sup>lt;sup>6</sup> Montgomery v Lanarkshire Health Board [2015] UKSC 11.

A number of respondents – including several representing healthcare staff, such as the Royal College of Nursing and the Royal College of GPs – called for a standalone assisted dying service. This is discussed in more detail in the "Delivery of an assisted dying service" below. However, this was seen as a way of avoiding adding to current pressures within the NHS, ensuring an adequate funding stream and fully protecting the right of healthcare staff to conscientiously object to participation in assisted dying.

# Lack of clarity on how an assisted dying process will be delivered

A number of respondents – some of whom were neutral on the issue of assisted dying – criticised the lack of detail in the Bill about how assisted dying would be delivered in practice. Scottish Hospices Leadership Group criticised the lack of detail around how an assisted dying service would be structured, hosted, regulated and funded. This prevented it from providing a fully informed view on proposals.

The Pharmacists' Defence Association and the Royal College of Nursing raised similar concerns about the expected involvement of their members. NHS Education for Scotland discussed training requirements and the potential need for a very wide range of NHS staff to be aware of assisted dying requirements. The Church of Scotland noted their role as a care home provider and asked about the expected role of care homes – in particular what safeguards there would be for other residents, staff and visitors.

An individual NHS consultant respondent commented on the risks to this approach:

"Some may argue that Bill is not written to describe exactly how assisted dying will be delivered and that it leaves it open to the appropriate government ministers to enact through direction within current NHS structures. I would argue that if assisted dying is to be delivered within current healthcare structures then parliamentarians require to understand and debate the evidence of whether this is safely achievable." (1AY5-M)

However, Friends at the End suggested processes for implementing assisted dying had been left deliberately vague in the Bill because healthcare services would be better placed to make decisions about delivery than policy and law makers.

# Cost-pressure risks

A key concern of those who opposed the Bill, and some who were neutral or supportive, was that assisted dying would be favoured over other treatment options because it saved money. Some saw this as an accidental "perverse incentive". In the words of one individual respondent:

"I am very concerned that it is cheaper to end life than it is to support it. How can a state not react to that incentive?" (1396-7)

However, others perceived it as a key motivation for the Bill. A number of respondents who opposed the Bill argued that assisted dying was just a way for the

state to reduce the costs of caring for elderly and disabled people. One individual respondent commented:

"When a government wants to help its citizens kill themselves, it becomes their enemy." (1JRG-8)

Several individual healthcare practitioners described the cost pressures they already faced in getting treatment for patients. There was a view that the availability of assisted dying would make it more difficult to get treatment for some vulnerable patients, in particular elderly ones. Some respondents noted existing practice of referring to patients with significant medical needs as "high resource individuals".

It was also noted that providing palliative care was expensive and time-consuming. This created an incentive to prioritise assisted dying, which was open to abuse in face of the current economic challenges facing health services.

Disability organisations and disabled individuals discussed the difficulties disabled people faced in accessing appropriate care and support already. It was argued that decisions are already being made on the basis of budgets rather than the best interests of individuals. In this context, a further incentive to save money was not appropriate.

The Church of Scotland was among those highlighting the current "care crisis" (that budgets for care services, social services and support to unpaid carers are under severe pressure). This had already led to people being made to feel a burden when their care packages were cut to balance the books. It said:

"We are an organisation which fundamentally supports personal autonomy as it relates to the principles of choice and control and believe that all people have the right to a full life and dignified death. However, we are alert to the fact that the right to good support, which can help achieve both of those ends, can be eroded in situations where other factors take priority."

An individual respondent asked:

"Will this Bill make it possible to access an assisted death sooner than a GP appointment, home care, a social work assessment?" (1XFH-B)

# POTENTIAL IMPACT ON SUICIDE PREVENTION ACTIVITIES

## Summary

There was concern among respondents who opposed the Bill about the impact of legalising assisted dying on suicide prevention activities. A number of respondents thought the move was morally contradictory – or would encourage more suicides. However, it was also argued that legalising assisted dying would prevent some suicide attempts.

The Scottish Association for Mental Health highlighted that discussion of assisted dying may raise issues for people living with thoughts of suicide. It

noted it was important not to use stigmatising language or conflate the two issues. SANE emphasised their view that there was a clear difference between suicide and assisted dying.

#### **Moral difficulties**

A number of respondents who opposed the Bill saw it as morally problematic for the state to say that suicide (as they saw it) was OK in some circumstances. This was argued to undermine existing suicide prevention work and to risk changing society's attitude to suicide more generally.

In the view of the Religion and Morals Committee of the Free Church of Scotland, it was contradictory for the state to try to fight against suicide while also enabling it with its own hand. The Bishops' Conference of Scotland was concerned that legalising assisted dying "suggests that sometimes suicide is an appropriate response to an individual's circumstances, worries and anxieties."

Some saw this as a two-tier system – suicide prevention for those whose lives were deemed to be worth living and assisted dying for those whose lives were not given this value. Anscombe Bioethics highlighted situations in Canada where, in its view, people who would in usual circumstances be considered to have mental health problems, were offered Medical Aid in Dying rather than suicide prevention.

## Impact on suicide rates of legalising assisted dying

The impact on suicide rates of legalising assisted dying was hotly contested between respondents who opposed and supported the Bill. Research which supported the conclusion that unassisted suicide rates had increased in US states which legalised assisted dying was heavily quoted. This suggested a general increase in suicide rates, particularly amongst women.

However, the Scottish Association for Mental Health was of the view that wider research shows mixed results. In particular, there appeared to be differences between the USA and Europe. It speculated that the reasons for this could be that European assisted dying regimes cover a much wider range of people, or that there was easier access to guns in America.

## The potential role of assisted dying in preventing suicide attempts

Some respondents who supported the Bill argued that legalising assisted dying would reduce the number of suicide attempts. This was based on evidence that people sometimes committed – or attempted to commit – suicide to avoid an end of life experience which was unacceptable to them.

They quoted statistics showing higher rates of suicide for people with certain terminal conditions. SANE referenced a Dignity in Dying report which estimated that hundreds of dying people were taking their own lives in the UK each year.

DIGNITAS argued that providing access to assisted dying prevented people from using risky DIY methods to end their own lives. The National Secular Society noted the risk from failed suicide attempts by people who lacked the means or expertise to end their lives in a peaceful and dignified manner.

# POTENTIAL IMPACT OF ASSISTED DYING ON FAMILY AND FRIENDS

Summary

Another concern from some respondents who opposed the Bill was the impact of assisted dying on family and friends. Issues included that there could be disagreement between family members about whether assisted dying was the right approach; or that people may feel guilt for not having supported a loved one in a way which avoided an assisted death.

There was also a view among some respondents that spending time with, or caring for, relatives even if they were struggling at the end, was a worthwhile experience. Shortening this time reduced opportunities to be with dying relatives. One individual respondent commented:

"To edit these times of life could contribute to a less caring, more selfish, and shallower society in my opinion." (174S-3)

Some respondents also discussed what they saw as a fear of death in modern society. Some argued that the Bill fed into those fears rather than supporting a more open approach to the end of life. An individual consultant neurologist commented:

"There is great ignorance in our culture about how diseases progress and how people die when they have good medical care. I believe this bill will continue this and will lead to unnecessary shortening of lives and lost time with loved ones in anticipation of an unlikely future." (16ED-4)

Respondents who supported the Bill argued that being able to control the time of death enabled those at the end of their lives to prioritise good quality time with family and friends. It may also spare relatives the trauma of seeing someone in significant discomfort.

However, a number of respondents recognised that the bereavement experience of those whose loved one had accessed assisted dying might be different from other experiences of death. There were calls for specific bereavement support, which is discussed in more detail in the Delivering an assisted dying service section below.

# ALTERNATIVES TO ASSISTED DYING

#### Summary

Many respondents who opposed assisted dying argued that alternative approaches were available. These included discussion of access to appropriate pain relief, care services and independent living support (funded support for disabled people to enable their fuller participation in society). However, the vast majority of comments related to palliative care services. A significant number of respondents called for the Scottish Parliament to deliver increased funding of palliative care services rather than support the Bill. Concerns included that palliative care was currently underprovided and underfunded, so people at the end of life did not have equal access; and that introducing assisted dying would undermine palliative care provision.

#### Effectiveness of palliative care

The Scottish Council on Human Bioethics argued that distressing symptoms can be relieved in around 95% of cases. It noted that people who want to die when they start receiving palliative care often feel better once their symptoms are better managed. It also flagged the role of palliative care in addressing patients' emotional and spiritual needs.

Better Way quote their collaborator Dr Juliet Spiller in describing the benefits of palliative care:

"I have been working in palliative care for twenty years and in this time, I have seen so many people come through crisis and despair to an end of life that included so many amazing things. I've seen families come together, I've seen conversations happen that would never have happened in any other situation, I've seen amazing memories created, I've seen families working through hard times. It brings people together. I would hate for any individual to miss out on these opportunities."

Some respondents highlighted concerns that there was a lack of awareness – even among those working in health services – about what palliative care could do.

However, the Humanist Society Scotland was among those noting that palliative care cannot relieve all symptoms for all patients. In their view, even with excellent palliative care, there was still a need for assisted dying. Compassion and Choices noted that the medication needed to relieve pain may be so strong that the patient is left unconscious. This results in some patients choosing to forgo medication in order to be present during their last few days of life.

#### Unequal access to palliative care services

Respondents across the spectrum of support for the Bill noted that provision of palliative care services was unequal, both in terms of funding and geography. This meant that many people did not get access to appropriate palliative care. The British Islamic Medical Association's view was that palliative care suffered from "chronic underfunding". The Royal College of GPs highlighted research showing significant unmet need. The Queen's Nursing Institute Scotland called for a "commitment to the provision of accessible, holistic, compassionate palliative and end of life care, which requires significant resourcing."

It was also noted that some palliative care – hospice care in particular and some specialist nurses – was provided by third sector organisations rather than the NHS.

Sue Ryder highlighted significant budget deficits among third sector providers, raising genuine concerns that some services may have to shut. The Free Church of Scotland was among those calling for NHS funding for these services.

The Scottish Hospices Leadership Group took a neutral approach to the issue of assisted dying. However, it did not want people to choose an assisted death because they could not access good palliative care, or because they were unaware that the option even existed. It called for the Bill to explicitly link a legal right to assisted dying with a right to good palliative and end of life care.

#### Impact of introducing assisted dying on palliative care

There was a strong view among those who opposed the Bill that assisted dying would have a negative impact on current palliative care provision. This was mainly because of concerns that palliative care would be seen as too expensive when compared to assisted dying.

Several respondents highlighted that the UK is considered a world leader in palliative care. In their views, the introduction of assisted dying would inevitably reduce incentives to develop better services and research more effective treatments.

Respondents who opposed the Bill also highlighted reports that palliative care facilities which did not accommodate assisted dying had had public funding withdrawn in some other countries. The examples of Belgium and Canada were frequently cited. There were also concerns that staff who did not support assisted dying may leave palliative care services if they feel their reasons for working in the sector are undermined.

Respondents who supported the Bill disputed that introducing assisted dying had a negative effect on palliative care. Some highlighted figures showing palliative care provision was ranked very well in some countries and states which allowed assisted dying. Dignity in Dying Scotland quoted from Westminster's Health and Social Care Committee's 2024 report on assisted dying (paragraph 142):

"In the evidence we received we did not see any indications of palliative and end-of-life care deteriorating in quality or provision following the introduction of AD/AS [assisted dying/assisted suicide]; indeed, the introduction of AD/AS has been linked with an improvement in palliative care in several jurisdictions."

Respondents who supported the Bill also argued that palliative care and assisted dying were complementary. The National Secular Society noted that, in places where assisted dying is legal, it is still not used by the vast majority of terminally ill patients. Compassion and Choices noted that, in gradients, 90% of those accessing assisted dying there were in hospice care at the time.

# **REASONS FOR SUPPORTING ASSISTED DYING LEGISLATION**

#### Summary

Comments from respondents who supported the Bill are discussed under the key themes identified by those who opposed the Bill, where relevant. However, there was also a discrete selection of reasons given for supporting the Bill. These are discussed below, covering the general need for access to assisted dying, the personal nature of the choice and some comments on people who may be excluded by current criteria in the Bill.

#### Need for access to assisted dying

A number of respondents who supported the Bill recounted their experiences of caring for a loved one who experienced pain or distress at the end of their lives. They argued that assisted dying provided a humane alternative. The fact that this option was available for animals was frequently referenced:

"Any bill which allows some people at least the same level of care that we insist upon for animals, is a step in the right direction." (1XTB-K)

People also referenced their own situations in terms of having progressive conditions. One individual respondent with MS stated:

"I would like to live in the knowledge that the medical profession will do everything it can to relieve my pain and suffering, and that includes providing me with a medically assisted death." (1XT8-9)

#### Assisted dying is a personal choice

There was also a strong view among supporters of assisted dying that it was a personal choice. It was noted that no one has to have an assisted death, so those who don't support assisted dying can choose not to access it. As a former GP put it:

"This option isn't about me or my values or beliefs. Frankly, it's not about yours either. It's only relevant to those facing this choice and if this is something they would want." (1XN6-1)

Some respondents also cautioned not to let moral or professional objections from healthcare staff be too influential. An individual doctor respondent said:

"No doctor would have to compromise their personal beliefs should assisted dying become legal – provisions for conscientious/personal objection are well established in the proposed legislation. By the same token doctors should not seek to impose our personal beliefs onto our patients, the public or lawmakers." (1JVT-S)

#### **Expansion of criteria**

Some respondents who supported the Bill also called for eligibility criteria to be expanded. The biggest concerns were around access to people with long-term degenerative conditions such as Parkinson's and Motor Neuron Disease.

# ADDITIONAL COMMENTS ON THE BILL

Respondents across the range of views on the Bill made additional comments. These highlighted issues not previously addressed and potential improvements to the proposals in the Bill. They are discussed in more detail under the following themes:

- costs associated with the Bill
- delivery of an assisted dying service
- treatment of people with dementia
- use of language in the Bill
- role of the courts, oversight and challenging decisions
- other suggestions.

### COSTS ASSOCIATED WITH THE BILL

#### Summary

Some respondents to the call for views commented on their views of the costs associated with the Bill. Some comments directly addressed figures provided in the Financial Memorandum.

The <u>Financial Memorandum</u> is a discussion of the costs associated with the assisted dying model proposed in the Bill, provided by the Member in charge. <u>Some of the figures were updated in two letters</u> from the Member to the Health, Social Care and Sport Committee. Broadly speaking, the Member's view was that the Bill would be cost-neutral.

The key concerns were around an underestimation of costs in the Financial Memorandum and risks to palliative care funding.

#### Concerns that costs in the Financial Memorandum are under-estimated

Several individual respondents commented that the costs in the Financial Memorandum were unrealistic, or that it would not be possible for staff involved to deliver assisted dying in addition to their current responsibilities. The Mental Welfare Commission for Scotland was of the view that insufficient detail on the costs of setting up an assisted dying process had been provided, despite information from other countries being available.

The Royal College of GPs challenged the assumption that discussions around assisted dying could take place at regular GP appointments:

"This is a complex process, morally and emotionally, involving considerable time for technical assessment of capacity and coercion which can be challenging. We do not believe that this work can or should be incorporated into an already very busy and stressed service, without potential detriment to patient care and significant emotional, psychological and ethical pressure on GPs."

The Royal College of Psychiatrists in Scotland did not think that costs could be absorbed within existing budgets. It argued that the demand forecast in the Financial Memorandum may be a significant underestimation compared to the experience in Canada. For the likely area of work for its members – providing assessments of capacity where there was doubt – it was of the view that requests would come in the form of unfunded and urgent requirements, challenging already stretched resources.

It also challenged the view that that the impact of the proposals would be cost neutral for those involved in assessments. This is because any potential savings would relate to end of life care. It said:

"It also neglects the fact that while the actual process of delivering AD/AS [assisted dying/assisted suicide] may be cheap, and it may avoid the cost of helping someone remain alive, the costs of assessing people for AD/AS may well be substantial, and will fall on services which do not benefit from cost reductions."

NHS Education for Scotland is responsible for education and training among NHS staff. It argued that first year training costs of £200,000, with minimal expenditure thereafter seemed "unrealistic". It identified a wide range of ongoing training needs, covering, for example, delivery, communication skills, bereavement support and staff wellbeing and trauma. It further noted that, if specific funding for these requirements was not provided, training in other areas would need to be reduced to deliver them.

#### **Risks to palliative care funding**

Another concern, expressed by a number of respondents to the call for views, was that funding assisted dying would reduce the money available for palliative care.

Anscombe Bioethics stated:

"... it is clear from other jurisdictions that there are immediate financial costs to implementation in terms of training and time taken for various assessments, completion of reports and other parts of the process, as well as the sourcing of lethal drugs and auditing of their use. If assisted suicide is construed as part of healthcare, as it is in the current Bill, then these costs will be taken from the healthcare budget (specifically the end-of-life care budget) and will be competing with resources provided to palliative care."

The Scottish Hospices Leadership Group noted that hospices get the majority of their funding from charity fundraising. Its view was that the introduction of assisted dying would have an impact on this: "There is a growing sense from some hospices that if Assisted Dying is legalised then hospices could see their fundraising efforts impacted."

It called for more sustainable funding for hospices from the Scottish Government to address this.

Hospice UK had further concerns about any assumption that the Bill would be cost neutral. In its view, no additional money would be available for palliative care unless a positive decision was made to re-allocate it. If the Bill were to progress to Stage 2, it called for a clear commitment from the Scottish Government that there would be additional funding for palliative care.

# **DELIVERY OF AN ASSISTED DYING SERVICE**

#### Summary

Respondents to the call for views made a number suggestions around the delivery of an assisted dying service. A key suggestion, in particular among organisations representing health professionals, was that assisted dying should be delivered as a stand-alone service, rather than be integrated into other health services.

Other comments covered: the involvement of other professionals in the assisted dying process; how to best support people to articulate their wishes and navigate assisted dying requirements; and consideration of specialist bereavement support. A further issue was the impact of requiring a health professional to stay with the patient until they made a decision as to whether to take the lethal substance.

#### Assisted dying as a stand-alone service

A number of respondents to the call for views made reference to a stand-alone – or opt-in – system for delivering assisted dying. It was supported by the Royal College of Nursing, the Nursing and Midwifery Council and the Royal College of GPs, among others. This would involve a service delivered separately from any existing NHS care. It was highlighted that this is the model to be legislated for in Jersey. Some Australian states also provide elements of a discrete service.

The option of an opt-in system was often discussed in the context of conscientious objection. In order to ensure health professionals could properly exercise their right to conscientiously object, it was argued that providing a separate system – so there was no ongoing impact on other forms of NHS care – was the most effective option. Some respondents argued that high numbers of staff were expected to exercise their right to conscientiously object. This may mean that an assisted dying service could not be delivered unless healthcare staff without a conscientious objection were specifically recruited to do so.

Having a stand-alone system was also seen as an effective way of ensuring staff involved had sufficient training to deliver assisted dying and ensuring funding for the service did not come from other parts of the NHS. The benefits were summarised by the Royal College of Nursing as:

- "Nurses who do not wish to participate in assisted dying would not face any pressure to do so.
- All staff who opt-in to the service would receive high-quality, specialist training and would gain valuable experience delivering the service.
- Staff could be better provided with specialist wellbeing support and access to a peer support network.
- Patients would have a clear pathway for accessing the service and would be less likely to experience staff exercising a conscientious objection.
- Patient choice about the timing and place of an assisted death could be better accommodated by a dedicated service.
- The establishment of a dedicated service would enable staff to travel as and when required to support the delivery of assisted dying in rural and remote areas.
- Existing services are under resourced and struggling and this cannot simply be added to existing workloads."

The Royal College of GPs saw a stand-alone system as also supporting a multidisciplinary approach, as well as facilitating research and clearer oversight.

Some respondents discussed their views on the best setting for assisted dying. The Royal College of Physicians and Surgeons of Glasgow argued that this would not be a hospital or primary care environment. The Scottish Hospices Leadership Group discussed concerns about offering assisted dying in a hospice setting, as well as potential risks to hospices if they didn't participate.

The Royal College of Physicians of Edinburgh discussed a model of service delivery which sat with the courts rather than healthcare professionals. This was sometimes referred to in other comments as a "civic model" of delivery. The role of the courts is discussed in more detail in the "Role of the courts, oversight and challenging decisions" section below.

#### The role of other professionals in delivering assisted dying

Edinburgh Napier University Centre for Mental Health Practice, Policy and Law Research questioned what they see as the assumption in the Bill that the process would be GP-led. They anticipated that many GPs would opt-out of providing a service. In addition, people may have a stronger relationship with the doctor responsible for their specialist care.

Edinburgh Napier University Centre for Mental Health Practice, Policy and Law Research was also concerned that the current delivery model would result in overmedicalisation of the process. They noted that modern medicine is multi-disciplinary, with nurses, social workers and psychiatrists all having expertise relevant to assisted dying. This was particularly relevant to the assessment of capacity and coercion. Social Work Scotland also supported a role for social workers in this process.

In the view of the Nursing and Midwifery Council, there was no reason why nurses, with appropriate training, could not have a wider role in the process than envisaged

in the Bill. An individual respondent noted the involvement of Nurse Practitioners in the assisted dying process in New Zealand. In their view, using nurses would increase accessibility for communities with barriers to accessing medical care. DIGNITAS asked if there were other professionals – such as nurses, social workers or what they called "death doulas" (doulas give practical and emotional support during the process of having a baby) – who could deal with requests for assisted dying.

#### Support to express views and to access assisted dying

Several respondents called for more support to be available to those navigating the assisted dying process. Scottish Hospices Leadership Group noted that approaching death and bereavement are recognised factors in increasing someone's vulnerability. It called for more to be done to support safe and appropriate decision-making at this time.

Several respondents, including the Equality and Human Rights Commission, noted that independent advocacy is a proven way to help people exercise capacity. It called for the Bill to include a right to independent advocacy. The Scottish Association for Mental Health noted that there was precedent for a legal right to independent advocacy in mental health legislation.

An individual respondent described the role of the Assisted Dying Advocate in Victoria, Australia and argued this significantly improved the support available to patients and their families:

"An Assisted Dying Advocate is a trained professional who supports patients and their families throughout the assisted dying process. Their role is to ensure that the patient's rights, autonomy, and well-being are prioritised, and they provide crucial support in navigating the legal and medical complexities of the process." (1QT3-W)

Given their involvement with the patient and their families, the Assisted Dying Advocate could also have a role in spotting coercion.

The Neurological Alliance for Scotland noted that people could lose their ability to communicate early on with some neurological conditions. It called for consideration of communication issues to be built into the process. This could involve early conversations with doctors when someone still had the ability to communicate. The use of communication support could also be considered. However, it cautioned that some assistive technology may not give access to the vocabulary necessary to express the nuanced views necessary in this situation. Similar concerns were expressed by Age Concern and About Dementia in relation to language support for people whose first language was not English. A participant had noted that there was no translation for assisted dying in their language.

#### **Bereavement support**

Some respondents who opposed the Bill were concerned that, because assisted dying was, in their view suicide, there could be a specific additional impact on family

and friends. They discussed the guilt they saw as associated with dealing with a death from suicide.

However, respondents with a wide range of perspectives on the Bill called for specific bereavement support for people whose loved ones had had an assisted death. Dignity in Dying Victoria noted that relatives who had contacted traditional bereavement support services in their state had not always been supported effectively. They were among those calling for this need to be addressed in other jurisdictions.

NHS Education Scotland noted that there was evidence that bereavement related to assisted dying raised some particular issues, including moral conflict, guilt and disenfranchised grief (although there were also positive aspects).

A number of bodies representing health professionals also highlighted the need for specific bereavement support. This was often argued to need to cover professionals involved in the process as well as friends and family members of those who had had an assisted death. There were also concerns about the impact on care staff and service users – eg. other residents in a care home.

# Requirement for the co-ordinating registered medical practitioner or an authorised health professional to stay with a patient until they have taken the lethal substance

The Bill requires the co-ordinating medical practitioner – or another health professional authorised by them – to supply the lethal drugs and to stay with the patient until a decision has been made about whether to take them. If the legal drugs are taken, the health professional must stay with the patient until they die. The health professional does not need to be in the same room as the patient.

Several respondents commented on the resource implications of this requirement. Patients would likely want to spend some time with friends and family before they took the substance and may, in some circumstances, take some time to reach a decision to take the drugs. It would also be important that patients did not feel rushed. Living Well and Dying Well commented that, in rural areas, health professionals would potentially have to travel to a patient's home and stay with them for hours as part of the process. It asked how this would fit in with their other duties.

It was noted that this was not a requirement in assisted dying regimes in other countries. Indeed, in many other countries, patients are given the lethal substance to take in their own time. Figures from other countries suggested around one third of patients were given a prescription of lethal drugs but did not take them. This was seen as an additional advantage to the system – a safeguard for people who were concerned that their pain or other symptoms might become unbearable. An individual palliative care expert from Australian commented:

"Across all states in Australia, about one third of those who start the process for VAD [Voluntary Assisted Dying], and who are eligible, do not to proceed to taking or being administered the VAD substance. Some seem to have been content knowing that they now had control of their fate and chose not to exercise that option, perhaps because they found that the care that they received from palliative care did relieve their suffering and they were content to let nature take its course. Others deteriorated suddenly and unexpectedly, and/or may have lost capacity before they died ..." (1XKU-W)

#### Other potential safeguards

Other suggestions for improvements to the assisted dying process included:

- a requirement to explore in more detail why a patient wanted to access assisted dying – some respondents suggested this could be done in a specific counselling session or with the support of a mental health professional. This may bring up issues – such as preventable symptoms or lack of support – which could be addressed in other ways. The Neurological Alliance suggested that involvement of a mental health professional would be a useful resource for both the patient and their family.
- a cooling off period after receiving a terminal diagnosis an individual doctor respondent commented that people are often distressed at the point they get their diagnosis and are therefore more likely to make impulsive decisions.

# TREATMENT OF PEOPLE WITH DEMENTIA

#### Summary

A number of comments from respondents covered how dementia would be dealt with under the Bill. The key issues were whether a dementia diagnosis was covered by the Bill, and how advance directives (stating how someone wanted their care needs to be addressed in the future) and the fluctuating capacity of someone with dementia could be dealt with.

#### Treatment of dementia under the Bill

Better Way was among those respondents which thought it wasn't clear whether a dementia diagnosis would qualify as a terminal illness for the purposes of the Bill. In its view, it was a progressive, life shortening condition. However, it could also be seen as a mental health condition and therefore covered by the exclusion for "mental disorders" in the Bill. Alzheimer's Scotland noted that it was unclear if the definition of mental disorder (which links to the Mental Health (Care and Treatment) (Scotland) Act 2003) covered Alzheimer's.

The Royal College of Psychiatrists in Scotland called for further clarification of the requirement for an "advanced" condition in relation to dementia. In many cases, those with advanced dementia would have lost capacity so would not be able to access assisted dying. However, this would not always be the case in its view.

The Royal College of Psychiatrists in Scotland also noted the significant potential for getting a dementia diagnosis wrong, potentially allowing people to access assisted dying when they didn't need to. The risk that people with dementia might choose to

access assisted dying earlier than their symptoms required, in order to still have capacity, was also flagged.

There were concerns around dementia as a co-morbidity with other conditions which would qualify under the Bill and whether this would automatically disqualify someone from being able to access an assisted death. The Neurological Alliance for Scotland noted that some neurological conditions have an increased risk of dementia.

#### Advance directives and assessing fluctuating capacity

Several respondents called for more clarity about the treatment of advance directives (statements about what care and treatment a person would want, made in anticipation of the fact they may lose capacity to express this as their condition progresses) under the Bill. The Bill does not specifically mention advance directives but they could potentially be used by someone with dementia – or other neurological conditions – to express a wish to access assisted dying at some point in the future. Note though, that the Bill as introduced requires someone to have capacity at the point they are given a substance to end their lives (as well as at all other points in the process).

Alzheimer's Scotland highlighted that this wasn't a straightforward issue. People may change their minds about wanting an assisted death as their conditions progressed. It was important to protect people who could no longer express their wishes.

Several respondents highlighted that a diagnosis of dementia of itself did not mean that a person lacked capacity. There were calls for consideration to be given to the assessment of capacity in situations where it might fluctuate.

Overall, this was thought to be a complex issue. Alzheimer's Scotland commented:

"The balance between protecting people who may be vulnerable and ensuring that people with dementia are able to exercise their legal capacity is challenging. Therefore, it is critical that Parliament is clear on its intention in relation to people with dementia and that it understands the implications of either including or excluding people with dementia."

# **USE OF LANGUAGE IN THE BILL**

#### Summary

A number of respondents who opposed the Bill criticised use of the term "assisted dying". There were also criticisms of other language used in this debate from those who supported or were neutral on the Bill. These included use of the term suicide and discussions of dignity.

#### Assisted dying was seen to be euphemistic

A key criticism was that using the term "assisted dying" rather than "assisted suicide". This was thought be some to be at best euphemistic and at worst a

deliberate attempt to avoid the real purpose of the legislation. Not Dead Yet UK stated:

"We should not sanitise the terminology in an attempt to make it more palatable."

The Free Church of Scotland was among those raising concerns that the public did not understand terms like assisted dying. Some thought it included existing options, such as palliative care and the withdrawal of treatment. In its view, this resulted in inaccurate indications of support in public opinion polls. Living Well and Dying Well was among those arguing that the public may understand the term to cover euthanasia (where a doctor or other person takes the active steps to end life) as well as assisted suicide.

#### Need for careful use of language in the debate around the Bill's provisions

The Neurological Alliance for Scotland noted that discussion of issues such as "independence" and "dignity" could be problematic for people with neurological conditions. It was important to be clear that the lives of people who needed support to carry out everyday tasks were not inherently less valuable or dignified.

The Scottish Association for Mental Health noted that the term "mental disorder" (which appears in the Bill linked to the definition in the Mental Health (Care and Treatment) (Scotland) Act 2003) was considered unnecessarily stigmatising by some people with mental health conditions. It noted that the Scottish Government was currently engaged in work to review and update a range of mental health-related legislation.

SANE argued that it was inappropriate and insensitive to conflate a wish to access assisted dying with suicide. It said:

"The difference between assisted dying and suicide troubles many people, and to conflate shortening life with foreshortening death does a disservice to both suicide prevention and end-of-life care."

# THE ROLE OF THE COURTS, OVERSIGHT AND CHALLENGING DECISIONS

#### Summary

Respondents with a range of views on the Bill highlighted issues around the role of the courts in supervising decisions in relation to assisted dying; a lack of oversight mechanisms for those involved in assisted dying; and that there were no provision in the Bill for challenging decisions.

#### A role for the courts in supervising assisted dying decisions

Some respondents noted that the current Bill on assisted dying being considered by the UK Parliament requires all applications for assisted dying to have the consent of the High Court (England and Wales). There were calls for a court-based model in

Scotland too. Under such a model, healthcare professionals may be involved in assessing a patient. However, the final decision about accessing assisted dying would rest with the courts.

#### A lack of oversight mechanisms

Edinburgh Napier University Centre for Mental Health Practice, Policy and Law Research was of the view that oversight for assisted dying was weak, appearing to rely on the existing, limited and mainly reactive role of the General Medical Council. It suggested that local multi-disciplinary panels could be developed to monitor practice and review individual cases. An oversight or review panel is a feature of assisted dying processes in some other countries.

The Royal College of GPs called for an independent system of oversight, monitoring and regulation to be developed.

#### Provisions to challenge or appeal decisions

Edinburgh Napier University Centre for Mental Health Practice, Policy and Law Research highlighted the lack of any mechanisms to appeal or review decisions from doctors around accessing assisted dying. It thought that this might breach article 6 of the European Convention on Human Rights, which requires access to an impartial tribunal to determine civil rights and obligations. It flagged the provisions in Adults with Incapacity (Scotland) Act 2000, which enable anyone with an interest to challenge a treatment decision in relation to an adult with incapacity. The Campaign Against Assisted Dying noted that there was no process for concerned relatives to challenge a doctor's assessment that a person meets the requirements to access assisted dying.

The Equality and Human Rights Commission called for a redetermination process where there were disagreements between a patient and medical practitioner, or between medical practitioners. It also suggested that a process for reviewing unsuccessful requests could be introduced.

# **OTHER SUGGESTIONS**

Respondents to the call for views made a wide range of other suggestions for improving the Bill or the assisted dying process. These included:

#### Addressing the issue of current, unequal access to assisted dying

Some respondents noted that people in Scotland could access assisted dying at present, but only if they could afford to travel to countries such as Switzerland. Creating a process which would apply in Scotland was seen as addressing this problem.

It was also noted that people may be forced to access assisted dying earlier than they might otherwise have chosen in order to be fit to travel abroad. A further issue was the lack of any clear route to raise concerns about an assisted death which has taken place abroad.

#### • The need for accurate information about assisted dying

Some respondents noted that, if legislation progresses, different assisted dying processes and eligibility criteria are likely to be in place in different parts of the British Isles. It was suggested that there was a need for clear communication – to professionals and the public – of the differences. The Royal College of GPs called for an official body to provide factual information about assisted dying, in part to ensure patients have accurate and objective information to aid their decision-making on this subject.

An individual respondent noted that New Zealand bans media reporting of assisted deaths. They noted that this may not encourage transparency and open discussion, but that consideration of an appropriate approach should be given.

#### • Dealing with legal issues around suicide

Some respondents noted that there may be insurance or other legal impacts of having an assisted death, if it were treated as suicide. There were calls for these issues to be addressed directly in the Bill. One respondent noted that Western Australian legislation specifically states that someone who dies under their assisted dying regime "does not die by suicide".

#### Heteronormative concepts of family

Age Scotland and About Dementia, as well as Edinburgh Napier University Centre for Mental Health Practice, Policy and Law Research highlighted the use of heteronormative terms to describe family relationships in the Bill. The definitions were used to describe who cannot be a witness to an assisted dying declaration. They rely on relationships of blood, whereas people who are LGBTQ+ may have a "family of choice" featuring people who are similarly close to them but who would not be covered by the definitions in the Bill.

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