End of Life Assistance (Scotland) Bill

Scottish Disability Equality Forum (SDEF)

The Scottish Disability Equality Forum (SDEF) works for social inclusion in Scotland through the removal of barriers and the promotion of equal access for people affected by disability.

It is a membership organisation, representing individuals with any type of impairment, disability organisations and groups who share our values. It aims to ensure the voices of people affected by disability are heard and heeded.

SDEF promotes access in its widest sense, including access to the built and natural environment and access to the same opportunities as are enjoyed by other people in our community.

Introduction to evidence

SDEF has consulted widely on the issue of assisted suicide and the specific contents of this proposal. We would like to make it clear that the views of our members on this issue are diverse and that no consensus has been reached.

Overall, slightly more than half of those who responded to the consultation were in favour in principal of some kind of relaxation of laws criminalising assisted suicide. Of this group, very few were entirely satisfied with the Bill as it is currently presented and their views are presented below.

Some of our members who are opposed to any change to the law on assisted suicide were concerned that a response from SDEF making suggestions about either procedural or substantive changes might be seen as tacit support and approval for the principles of the Bill on behalf of SDEF. We would like to make it clear that this is not the case. With this response, SDEF merely seeks to put forward the views of its individual members.

- Are you satisfied with the two categories of people who would qualify to be assisted under the terms of the Bill?

Of the two categories of eligible persons it was the second which provoked the most reaction from our members. Section 4(2)(b) gives the right to make a request for assistance to those who are permanently incapacitated to such an extent as to not be able to live independently and find life intolerable.

Our members were divided on this provision. Many felt that it would bring the rights of those who are physically incapacitated in line with those of able bodied people, in that they would be able to choose when to end their lives. One stated:
“At the end of the day, this is a choice that everybody should be able to make themselves. I don’t want other people telling when I can and can’t end my life. It’s my choice. No-one else’s”

Another said:

“As far as I am concerned, my life belongs to me, not any elected official. Therefore, if I chose to either put my life at risk by performing a certain activity, e.g. driving a car, crossing a road, parachuting, etc. or by extension, to end my life, it is my own choice. Therefore, if I am in a condition that I am no longer able to take control of my own actions to end my life, I still feel that I have the right to make the decision to request aid to perform this function.”

Many felt there should be as much choice as possible, as early as possible for those who had disabilities or degenerative conditions. They felt in many cases that legislation might extend rather than shorten lives.

“If end of life assistance is not made available I will have to end my life earlier than I wish while I still have enough physical function to carry out suicide. I am grateful beyond words to those fighting for assistance to be made available.”

Indeed, this was borne out by an example given by another member who stated:

“A friend took her life recently - probably before she needed to die. Her family was devastated and felt they had failed her. If it had been possible here in the UK (she was unable to travel abroad) they could have been involved in the decision and prepared for the event”

Despite this support for the Bill, many others were extremely concerned about use of the term, ‘incapacitated to such an extent as not to be able to live independently’

Our members clearly made the point that the barriers to independent living in Scotland are numerous and extremely complex. It is not always illness or incapacity that makes independent living impossible, but rather societal and physical barriers and a lack of care and support. Some of our members related this to a need for government and society to embrace and understand the social model of disability. They felt that to accept that a person’s life would not be worth living because of their disability or condition was not acceptable when many of the factors that make people’s lives intolerable and prevent them from living independently are in fact external and improvable. This sentiment is eloquently expressed by Jim Elder-Woodward’s article in the Scottish Herald

“To hear Margo MacDonald use the absence of independent living as an advocate for death and dying makes the blood of many disabled people run cold. Elements of Independent Living are now enshrined as “rights” under the UN Convention of Rights of Disabled People; it is the absence of such rights which makes life intolerable, not physical incapacity. It is quite wrong of
people to think that being denied such rights to live, should give disabled people the right to be assisted to die. If this bill becomes law, it won’t be their impairments which will cause them intolerable pain and discomfort, but a society which has turned its back on them; and points to the exit door.”

One of our members also stated:

“...I think society should be working to ease the lives of people with disabilities, i.e. free personal care, more support etc. As somebody who has been disabled for over 24 years, I feel society has stepped backwards in many of its positive attitudes to disabled people, and much of the “care in the community” support that was put in place to ensure people could live independently in the community is gradually being diminished and sometimes withdrawn making it increasingly difficult for disabled people and their families. This makes disabled people feel guilty at the cost and burden it puts on families, and it worries and scares me what the implications would be should the right to die with assistance became law.”

Some members raised the possibility of a ‘rights worker’ or ‘key worker’ being allocated to any physically incapacitated person who had asked for assistance in ending their life. This worker could help to ensure the individual was accessing all services and entitlement available to them which might assist them to live independently and make their life more tolerable.

Another issue which was raised again and again was that of disabled people feeling burdensome and sensing that there was pressure on them to end their lives. This was often the result of family members struggling to cope with caring responsibilities or financial pressures.

Some of our members stated that they themselves had experienced feeling burdensome and that at its worst it had left them wondering “whether to end it all would indeed be the best thing for everybody concerned”.

Some respondents felt that as well as looking at means of facilitating independent living was a need to address care issues, support for carers, respite care and community and social care provision for family members to allow them to live their own lives and continue with their caring responsibilities.

Furthermore several of our members commented that the only moral justification for including those who are physically incapacitated in the Bill was if they were physically incapable of carrying out the act of suicide itself. Otherwise, they felt there could be no moral distinction between able bodied and the physically disabled people in relation to assisted suicide. They suggested replacing the phrase ‘physically incapacitate to the extent that they are not able to live independently’ with the phrase ‘physically incapacitated to such an extend as they are not able to end their lives without assistance’ – or similar.
• The Bill outlines a several stage consent and verification process that would be required to be followed for an eligible person to receive end of life assistance. Are you satisfied with this process?

Time Limit

In relation to the consent and verification process the main concern of our members appears to be the making of a second request between 15 and 30 days after the first. The majority of those who responded thought that this was an insufficient period to confirm such a decision, particularly given the risk of depression and mental health problems amongst those considering suicide. One commented that:

“you usually have 31 days to change your mind about returning a sofa and surely this was a more important decision. It also take years to convince the NHS you need a sex change. 14 – 28 [sic] days just isn’t long enough.”

Many of our members who responded to our consultation on the Bill said that they had experienced deep depression and even suicidal feeling upon diagnosis but that these feeling had eventually passed and that they had adapted to their new circumstances and come to enjoy full, active and fulfilling lives. Many members stressed the need for support and counseling for those who wanted to end their lives. Again, the point was raised that more support must be given to enable disabled people to live independently. Some of their experiences are recounted below:

“Some people could have a knee jerk reaction to their condition and without real insight or knowledge of how their life could be, may want to end it. I know from experience that I had always said that I would not want to live with any disability. Life would not be worth living and I would want it to end. When I lost my sight, I presumed my life was over. However, with good support, rehabilitation and meeting others with the same condition as me, I realised that life was indeed worth clinging on to. It is important in these cases to ensure that all support is offered. Especially psychological support. That every possible programme has been offered to that person, before any consideration to assisted suicide can be made.”

Another commented:

“As somebody who became paralysed at the age of 21, now over 24 years ago, I felt deeply disturbed when the young rugby player who had been paralysed ended his life with assistance. I look back to when I found myself paralysed, vulnerable and feeling as if my whole world had come to an end, and feel very relieved that there did not seem to be the acceptable choice to consider ending my life with assistance at that point in time. My experience of spinal rehab in the 80's was firm but positive, trying to prepare you for future life with a particular disability. I would be lying if I said I had never considered suicide, but this wasn't until about 10 years on, at a time of feeling isolated and down, but with help and support it became easier. As a disabled person you are at times very vulnerable, and I am deeply troubled by the debate that
is going on about the end of life assistance especially when at the same time so many cuts and changes are being made in the help and support to both the disabled and the elderly.”

In relation to terminal illness there was less comment on time periods. However, one member did state that:

“The window being offered for providing assistance is apparently small. First someone has to be deemed to have less than 6 months to live, then the process has to be concluded, which appears to take at least a month. It would be better to focus on optimising terminal care and quality of life for that time. The highest profile example of life expectancy assessment has proven woefully inadequate. The Lockerbie bomber was repatriated on compassionate grounds, with less than 3 months to live, 6 months ago. He is still alive! We do not choose to be born, nor do we expect to choose what conditions affect us during our life. Death should remain at that same level of mystery, beyond our choosing.”

- Do you consider the level and nature of safeguards as set out in the Bill to be appropriate?

Procedure

Many members that no safeguard or procedures would ever be sufficient to eliminate the risks involved in assisting people to end their lives. One member commented:

“This proposed bill to me would very soon lead to massive abuse. The bill does not have the safeguards that the 1967 Abortion Act has and yet we know how meaningless they have become. How many of those who might say that they wanted to die would in fact simply have needed diagnosis and treatment of depression? Would the doctors or the psychiatrist who may never have met the person take the time for a proper examination or evaluation taking everything into account? “

Some felt that there was also a risk that mistakes would be made, particularly where people with extreme communicative difficulties are involved. One stated

“This is an extremely dangerous route to follow, particularly with relation to disabled people. Although there is much in the bill about safeguards, it is likely that many potential users will have extreme communication difficulties, and the possibility of misunderstanding, or misinterpretation has to be there, especially if someone goes through the process then changes their mind.”

SDEF would like to reiterate the point that if any law relating to assisted suicide is passed it is essential that all information relevant to the Bill be made available and publicised in a range of formats including BLS, Easy read, audio, video etc. This should be the case with any documents involved in the process of requesting assisted suicide.
The other major concern amongst some of our members was that medical doctors were not in the best position to make decisions relating to assisted suicide. Some felt that medical doctors do not always have a sufficient appreciation of disability and the lives of disabled people. A small minority said that the medical profession was representative of a certain sector of society – namely ‘middle-aged, middle-class and able-bodied’. They felt that certain doctors might not always attach sufficient value to the life of a disabled person or understand what it can mean to live independently and how this can be achieved. The group felt that there was a need for any doctors involved in the process to receive training in disability awareness and independent living.

Others were against doctors making decisions about who should be eligible for assisted suicide because they felt that to have such wide and subjective applicability criteria – such as inability to live independently - put an unreasonable burden on the doctors who would have to make the decisions.

“These decisions would not be based on a physical medical prognosis but rather on a judgement as to whether a person’s life was tolerable or not.”

Others felt that a wider range of people should be involved in making what were “essentially moral, value based judgments”. One stated that, “there should be an independent committee set up that consisted of people from all strands of the disability and equality sector. Whether that be made up of charity groups, professional groups, voluntary groups and patient focus groups from NHS. A bit like jury service where the evidence is heard and the independent committee sat in judgment of the facts.”

This view was by no means universally held. One members stated,

“Should I choose to end my life, I feel to have to have a group of people, who do not know me, stand in judgment and decide if I can or not somewhat insulting!”

Thank you for this opportunity to present the views of our members

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12 May 2010