End of Life Assistance (Scotland) Bill

British Psychological Society in Scotland

The British Psychological Society in Scotland is pleased to have the opportunity to respond to the Committee’s call for evidence on the proposed End of Life Assistance (Scotland) Bill (the Bill). The British Psychological Society (“the Society”), incorporated by Royal Charter, is the learned and professional body for psychologists in the United Kingdom. The Society is a registered charity with a total membership approaching 50,000, almost 3500 of whom are based in Scotland.

Under its Royal Charter, the objective of the Society is “to promote the advancement and diffusion of the knowledge of psychology pure and applied and especially to promote the efficiency and usefulness of members by setting up a high standard of professional education and knowledge”.

The Society is committed to providing and disseminating evidence-based expertise and advice, engaging with policy and decision makers, and promoting the highest standards in learning and teaching, professional practice and research. The Society is an examining body granting certificates and diplomas in specialist areas of professional applied psychology.

We are content for our response, as well as our name and address, to be made public. We are also content for the Scottish Government to contact us in the future in relation to this consultation response.

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This response was prepared with contributions from:

Mr James Anderson, Clinical Psychologist, Scottish National Spinal Injuries Unit; and Member of the Special Interest Group on Spinal Injuries

Dr Frances Baty, Chair Division of Clinical Psychology Scotland, Consultant Clinical Psychologist/Locality Head, Adult Psychology, West Fife

Dr John Higgon, Consultant Clinical Neuropsychologist, Head of Older Adult and Neuropsychologist Services, NHS Dumfries & Galloway; a Member of the Psychology Special Interest Group on the Elderly and Practitioner Full Member of the Division of Neuropsychology

And is co-signed by Dr Carole A. Allan, Chair, The Professional Practice Board of the British Psychological Society.
Do you agree a person should be able to request end of life assistance from a registered medical practitioner?

This submission should not be interpreted as support for the Bill from the Society. Psychologists hold a range of personal views on this issue but cannot offer a professional opinion on what is ultimately an ethical question.

Likewise, we have no objection to the Bill in principle. Our concerns to the Bill in its present form are with the practicalities and implications of it, as set out below.

It is difficult not to have great sympathy for those in that position who cannot end their life and yet believe they need to do so. We accept that there are many who believe that such people should be helped and that such assistance will inevitably be expected to involve medical professionals.

One area of work for clinical psychologists is around assisting people who suffer from spinal injuries and other physical disabilities to adjust to their condition despite adversity and clinical psychologists also have expertise in establishing mental capacity.

Any decision on whether or not to take this proposed legislation further must be based on the evidence as to patient benefit, and focus on putting in place the correct safeguards – including robust agreement on the process for assessing mental capacity – and coming to a decision based on the patient’s capacity to make an informed judgement, rather than professionals’ personal moral, religious or emotional sensibilities - we base this belief on our general support for the principle of individual autonomy.

Are you satisfied with the requirements for age and connection with Scotland as set out in the Bill?

We have no specific concerns regarding age. However we would wish to highlight our concerns below with reference to people who suffer physically incapacitating conditions and the time period that should reasonably be allowed for individuals to adapt to the condition, which can be affected by the age of a person.

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

We are seriously concerned about the manner and implications of the inclusion of people with physical disabilities within this Bill in its present form.

We feel that the Bill should include a clearer distinction between those who are terminally ill and those who have incapacitating (but not necessarily life-limiting) conditions.

We do not wish to comment on whether this assistance should in principle be offered to those with physical disabilities – that is a question for those with a
disability to decide, perhaps with the full knowledge and support of those who care for them.

But we do have concerns about the manner, safeguards and implications for including those with traumatic physical incapacity under the present provisions.

The Bill and accompanying documentation give much thought to the consideration of end of life assistance and for making the case for those with life-limiting or terminal disease.

By contrast, the inclusion of the physically disabled seems haphazard (in the Policy Memorandum they are not directly mentioned until paragraph 96) and there appears to be little thought about how those with a disability who are dying differ from those with a life-time of chronic physical disability.

Arguments about intolerable pain, hastened death and insurance against future loss are largely irrelevant to the lives of those with physical disability; for example a spinal cord injury is generally not life limiting and the inability to tolerate their lives can emerge from factors very different to those of terminal disease.

Research evidence suggests that many able bodied people over-estimate the intolerability of physical disability. To include the physically disabled in such a Bill without clear justification as to what is unique about their suffering seems to run the risk of reinforcing the worst prejudices about those with disability. In fact, intolerability in those with physical disabilities is often due to the vagaries and limitations of the services available rather than the condition itself.

There are references in the Bill and accompanying literature to the protection and development of palliative services. We believe there should be equal weight given to statements of protection and the obligation on local authorities, employers and the NHS to ensure appropriate services for persons who are physically disabled.

The process of adaptation to a physical disability can take many years. To offer an assisted death to people early in this process (as the Bill suggests it would) may undermine the ability and resolve for all those involved to engage with the long process of adjustment. We see this as potentially a serious loss and ultimately detrimental to individuals, their families and Scottish society. We would suggest a significant cooling-off period should be considered in such cases between the two requests for assistance, although we would believe that those with the disabilities in question are best placed to comment on this aspect of the Bill.

We are struck that no argument is made in the Bill or accompanying documentation to explain why people with physical disabilities, as opposed to people who feel their lives to be intolerable (for instance through mental
illness, chronic pain, bereavement or poverty) are alone regarded as warranting this assistance.

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?

We are satisfied that psychiatrists, psychologists and other specialist professionals have the skills to make the assessments outlined in the Bill with regards to capacity.

While various technical objections to the Bill have been raised, two of the most frequent objections are:

I. the possibility that the decisions of terminally ill patients might be subject to influence from family and;
II. the difficulty of establishing whether or not a terminally ill patient has capacity to make a decision about assisted suicide.

Clinical psychologists, by virtue of their training and clinical experience, have a significant role to play in the establishment of capacity. They are highly trained in clinical interview techniques and the use of standardised measures of mood and emotional disorder. They are trained to consider the origins of an individual’s behaviour, beliefs and wishes, taking into account a range of intrapersonal, interpersonal and contextual factors. They are well placed to assist their medical colleagues in arriving at an informed decision about the capacity of a patient who has made a request for end of life assistance, and on the basis on which that request is being made.

We would recommend that the onus be on healthcare professionals to go beyond using just clinical judgement to include standardised measures of capacity.

A parallel exists in the Adults with Incapacity Act, where medical practitioners call upon clinical psychology colleagues for an in-depth assessment of a person’s capacity in order to inform their final decision.

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

We have concerns about the impact on vulnerable newly injured people, their families and the engagement and commitment of all services if access to assisted dying (on the time frames for terminal illness) is permitted for those with physical disabilities.

Adjustment and recovery are difficult and expensive processes that take years. Over those years, however, independence, dignity and quality of life does improve for most, and this should be borne in mind with regards timescales for applications.
We are also concerned that the inclusion of those with disabilities within the scope of this legislation will have a damaging effect on disability services and charities – and society’s attitude towards those with a serious disability.

**Do you have any other considerations on the Bill not included in answers to the above questions?**

**Nature of people’s objections**

Much of the criticism of the Bill stems from religious beliefs about the value of life and God’s role in the giving and taking away of life. Sociological research shows that religious belief amongst the general population is in decline. For example, the 2007 UK Survey Data shows that 50% of the UK population believes in God and only around 33% describe themselves as religious. Of this 33%, 50% “do not practice religion very much, if at all”.

On the basis of these figures, it seems that criticisms of the Bill on the basis of religious belief cannot be regarded as necessarily a generally shared position of all people, and we ask that, in its consideration, the Committee will not confuse personal beliefs with evidence in considering this matter.

**Effects on palliative care provision**

The objection is sometimes made that the emphasis in healthcare should be on palliative care rather than end of life assistance. Psychologists would want to see the highest quality palliative care services in place and some clinical psychologists already play a significant role in such services.

However, there is no need to introduce a false dichotomy into the debate about end of life assistance. Palliative care may exist alongside end of life assistance measures and this would not represent a logical contradiction. The measures proposed in the Bill would augment the choices available to terminally ill patients, who, on account of the disabling nature of their illness, were unable to bring about their own deaths and required assistance to do so.

**The nature of intolerability**

The Bill and policy document explore the tensions between palliative care and assisted dying and recognise one should not exist at the expense of the other. Unfortunately similar thought has not been given to those who are physically incapacitated but who are not terminally ill.

For people with physical disabilities, intolerability often emerges due to social or environmental factors (quality and flexibility of care, housing and opportunities for community engagement) rather than pain and the reality and fear of increasing incapacity.

People with disabilities are at their best (as we all are) when productive citizens, engaged in family, work and leisure activities. This is achieved when physical care, home adaptation, community medical, nursing and social
support; and financing of appropriate changes to workplaces or retraining has been provided. We are proud to be part of a society, and to work within a NHS, where this occurs, and we would treat with due scepticism any measure which may dilute these efforts or does not explicitly protect them.

Irrespective of how well services are provided, it would be utterly unacceptable to consider allowing the provision of assisted dying for anyone with a terminal illness where there are not also appropriate palliative services offered as an alternative.

It seems equally abhorrent that assisted dying is offered to a group for whom intolerability can emerge from the state’s or society’s unwillingness to provide sufficient means of inclusion, without recognition or guarantees that such assistance can and will be provided.

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