Dying with dignity

Analysis of consultation responses
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Introduction

On 20th January 2005 the Death with Dignity Consultation was launched. The paper outlined the proposal to introduce a Member’s Bill which would allow competent adults, suffering from a terminal illness, and who make persistent and considered requests to die, the right to receive medical help to bring about their death.

The consultation paper put to the public the proposal that Physician Assisted Suicide should be legalised in Scotland. Current law in Scotland is inconsistent with regards its policy of assisted dying and suicide. The proposed legislation aims to clarify that legal position. It further aims to provide a statutory safeguard to prevent abuse and ensure that the law is applied appropriately.

The main issues that the proposed Right to Die for the Terminally Ill Bill would address include:

- That the Bill would only apply to ‘capable’ patients who are adults and residents of Scotland and that the term ‘capable’ would be defined using the Adults with Incapacity (Scotland) Act 2000.

- That it would be the duty of the doctor (or multidisciplinary care team in a hospice or elsewhere) to explain any feasible alternatives when the patient requests assistance to die – alternatives being pain relief, hospice support and other palliative care packages as available.

- That this legislation would apply to patients diagnosed with a terminal illness that will result in death within 6 months

- That no medical professional or health care authority would be compelled to participate in the Act

- That a reporting mechanism and an annual report would be required to be published detailing incidents of prescriptions, as well as results of interviews taken with those requesting the prescription

- That the patient is central to all medical treatment decisions

The consultation closed on the 15th of April 2005 and the following is a brief analysis of the responses received.
To assist in the analysis of this consultation, and in the interests of making a quantitative breakdown, submissions have been summarised into the following categories: support, opposition and neutrality. It should be understood that these have been categorised according to the comments made in each submission and by the judgment of the author. All quantitative results are therefore tantamount to that position.

No assumption is given as to the representative nature of each submission i.e. for representative organisations or professional bodies.
Summary

In total, 616 parties responded to the consultation 'Dying with Dignity' and the proposed Right to Die for the Terminally Ill Bill – an unprecedented number to a Member’s Bill. Submissions were made from NHS Boards, medical bodies, Local Authorities, Religious Groups and organisations, Elderly and Child Welfare organisations, euthanasia and pro-life interest groups and many hundreds of responses from medical professionals and private individuals.

An analysis of results shows that 346 respondents were in general support of Physician-Assisted Suicide (PAS) and a change in the law. 201 were opposed to the principle and to any change in the law. Whilst 69 submissions remained neutral, raising points or concerns or making suggestions, but not stating opposition or support for the purpose of a change in the law to allow terminally ill patients the right to die.

The general evaluation therefore shows the results of the consultation as being 56% in favour of the principles laid down in the paper, 33% opposed, and 11% neutral.

<table>
<thead>
<tr>
<th>Support</th>
<th>Oppose</th>
<th>Neutral/No registered position</th>
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<tbody>
<tr>
<td>346</td>
<td>201</td>
<td>67</td>
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<tr>
<td>56%</td>
<td>33%</td>
<td>11%</td>
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NHS Boards

Seven NHS Scotland Boards responded to the consultation. They included:
- Ayrshire and Arran
- Fife (personal view from Dr Stella Clark, Acting Medical Director)
- Greater Glasgow
- Grampian (individual response from Dr Gordon Peterkin, Cross Systems Medical Director)
- Highland
- Lanarkshire
- Lothian

Of those that responded, Dr Peterkin of NHS Grampian, fully supported the proposals, Dr Stella Clark of NHS Fife fully opposed the proposals and the remaining five were neutral. In percentages this equates to 71.4% neutral, 14.3% in support and 14.3% in opposition.

Arguments raised in this section include:

- That the conscience clause allowing doctors and local health authorities to opt-out of providing this service may produce a ‘post-code lottery’. This would mean patients in certain areas may not be able to have this right if their local health board declines to provide it;
- That it is a good thing that doctors will not be compelled to participate in the Act but believe health authorities should as there is a need to make the service available to all and;
- That Physician Assisted Suicide should be not be seen as an alternative to good end of life care, however recognise that not all suffering can be alleviated.
Local Authorities

Four Local Authorities responded to the consultation. They included:

- Aberdeenshire Council (individual response from Council officers)
- Falkirk Council (individual response from Council officers)
- North Lanarkshire Council
- Orkney Islands Council

Of those that responded, the response from individual officers at Falkirk Council was supportive of the proposals whilst individual officers at Aberdeenshire Council, and North Lanarkshire and Orkney Islands Council were neutral, equating to 75% neutral to 25% support.

The main point raised by the Local Authorities that responded to the consultation was that the protection of vulnerable adults needed to be the key priority. An issue that was also raised by two of the four Councils was that the proposals ‘conscience clause’ could deny access to PAS in areas where Health Boards or GPs declined to participate. This was raised particularly by Orkney Islands Council who perceived a difficulty in initiating this legislation in small island communities. It was also seen as discriminatory and an issue that must be considered in more detail in the progression of the legislation.

Also argued in this section was the need to recognise the role of the carer in this legislation and their legal position in the case of a patient being unable to self-administer the lethal dose.

It was also suggested that there would need to be a provision of a counselling service for patients to ensure that their decisions are not taken under pressure. With regards the financial implications arising from the legislation, the view was that there would be an increased burden on hospice and palliative services and further implications on the training of
staff, the need for support stuff etc. It was also believed that there is a need to consider the availability of resources for people who choose PAS i.e. hospice funding and local authority 24 hour support.

Medical Bodies

Fourteen medical bodies responded to the consultation. They included many of the Royal Colleges, the General Medical Council, the British Medical Association, the Scottish Council on Human Bioethics and the Disability Rights Commission.

Of the fourteen submissions a total ten were opposed to the proposals outlined in the Bill whilst four were of a neutral position, which equates to 71% opposed with 29% neutral.

It should be noted that, following their submission on 6th of April 2005, the British Medical Association altered its position on Physician Assisted Suicide (PAS) from a stance of opposition to one of neutrality1. It should also be noted that the Disability Rights Commission has stated that it does not oppose the principle of PAS or its legislation and supports the principle of patient autonomy. In light of this 64.3% of medical bodies are opposed to the principle of PAS whilst 35.7% are of a neutral position.

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1 The BMA Annual Conference took place on the 28th of June 2005. Conference passed the following policy statement with a vote of 53% in favour and 47% against:

"That this Meeting believes that the question of the criminal law in relation to assisted dying is primarily a matter for society and for Parliament. The BMA should not oppose legislation which alters the criminal law but should press for robust safeguards both for patients and for doctors who do not wish to be involved in such procedures."
Palliative Care Groups

There were a total 23 submissions in this section and included responses from individuals and organisations involved in palliative care. There were also submissions from the Scottish Partnership for Palliative Care (SPPC) and the Association for Palliative Medicine of Great Britain and Ireland.

Of those that responded 17 were opposed to the proposals outlined in the Bill whilst 6 were neutral, equating to 74% opposed and 26% neutral. The six neutral submissions were made from the following:

- Strathcarron Hospice, NHS Forth Valley
- A Consultant Physician in Palliative Care
- A Palliative Care Specialist nurse
- Two Macmillan Nurses, NHS Argyll & Clyde

The basic argument laid forth by the palliative care response is that this legislation is unnecessary as death with dignity is already achieved through symptom control and the holistic methods used in palliative and hospice care. The argument was also raised that the introduction of legislation to allow PAS will take away resources from palliative care services as PAS would provide an ‘easy way out’ and would be a cheaper service.

Concerns that were raised include:

- That this legislation will enhance the feeling many terminally ill patients have of being a burden;
- That depression is a major contributing factor to terminally ill patients’ requests to end their life. Depression however can be treated;
- That the relationship between the doctor/nurse and the patient will be affected due to this legislation. Trust in particular was
considered to be a factor that would be greatly affected by this legislation;

- That the proposals discriminated against incapable patients;
- That there was great difficulty in providing an accurate prognosis of 6 months or less to live;
- That there would be great difficulty in protecting the vulnerable if the legislation was passed and;
- That palliative care services are not widely available throughout Scotland and that, as a result, there would be discrimination against patients in certain areas who could not be offered all the alternatives to PAS.

The debate however was welcomed across the board as a means of leading to greater ease and openness in addressing end of life issues.

The SPPC also acknowledge that for a small number of individuals the existential and physical suffering of the dying process will not be relieved by palliative care, and that the issue of caring satisfactorily for these patients must be addressed.
Medical Staff (Individual)

Seventy Seven responses came under this section. They include responses from all individual medical professionals and medical students (minus palliative care staff). Overall 42 were opposed to the Bill, 16 were in support and 19 were neutral. In percentages this equates to 54.5% in opposition, 20.8% in support and 24.7% neutral.

Main arguments expressed from this section include:

- Patients might have a right to die but they do not have the right to expect medical professionals to prescribe the medication to help them die;
- Medical professionals have sworn the Hippocratic Oath to First Do No Harm and many feel this legislation would be contrary to the Oath;
- Any legislation to instigate PAS will alter the doctor-patient relationship and have an affect on the balance of trust between them;
- Legislation of this kind will result in a slippery slope – leading eventually to legalised euthanasia;
- There is a concern that the vulnerable will be affected by this legislation and that those who feel like a burden will feel compelled to request the right to die and;
- That life is fundamental.

Several submissions of support instigated the argument that animals are able to be put down to stop their suffering but humans are denied the right and that, as a result, this legislation is to be welcomed.
Religious Organisations

Twenty eight submissions were placed in this category. Responses came from many of the major faith denominations in Scotland including Christian, Catholic, Jewish, Mormon and Bahai. It also included responses from the Christian Medical Fellowship, the Nurses Christian Fellowship of Glasgow, one member of the Guild of Catholic Doctors, and a personal response from the Chairman of the Lawyers Christian Fellowship. As well as responses from religious organisations this section also includes submissions made by individual church groups and individuals who express a religious belief.

Of those that responded 23 were opposed to the proposals, 3 were in support and 2 were neutral, equating to 82% opposed, 11% supporting and 7% as neutral.

The main argument that respondents in this section made is that life is God given and has intrinsic worth. It is therefore morally wrong to hasten death through artificial means, to do so would be playing God. Further issues raised include:

- The social consequences that this legislation would produce. In particular the emotional pressures on a patient’s family and friends, the role of the medical professional in society, and the stigma that is attached to assisted death;
- The moral distinction between allowing someone to die and causing that person to die. In many cases respondents believed it was morally acceptable to allow someone to die by withdrawing treatment if it had become futile. They did not believe it to be morally acceptable to assist someone to die through a lethal prescription;
- Many terminally ill patients feel like a burden and this will contribute to that;
Many of the Christian faith denominations believed that a competent adult has the right to refuse treatment and;

That the Church has a duty to act with compassion and therefore believe that more resources should be provided to palliative care.

One submission of support gave the argument that the concept of God waiting to take one’s life when he is ready is outdated. We have the right, if the patient so wishes, to act with the mercy of God to bring hopeless suffering to a peaceful end.

The Baha’i Council of Scotland gave a neutral submission stating that their teachings indicate that God gives us life and that death is simply moving onto another stage of existence. There is nothing in the Sacred Scriptures regarding PAS and it is their belief that it should be left to the individual conscience to decide. They further believe that any legislation should be of a general nature in order to give the Courts plenty of scope to make appropriate judgements on individual cases.
‘Neutral’ Groups

Eleven responses were placed in this section. They included submissions from various interest groups such as the Scottish Motor Neurone Disease Association, the North of Scotland Cancer Network (NOSCAN), the British Geriatrics Society (Scotland), Marie Curie Cancer Care, the Parkinson’s Disease Society and Care for Scotland. Submissions were also made from the Association of Directors of Education Services (ADES), the Public Services Ombudsman and the Law Society of Scotland stating their neutrality to the legislation.

Overall eight of the submissions were neutral. These included the Scottish Motor Neurone Disease Association, NOSCAN and the Parkinson’s Disease Society of the UK. The three submissions of opposition were made by the British Geriatrics Society (Scotland), Care for Scotland and Marie Curie Cancer Care, equating to 27% opposed to the proposals, with 73% of a neutral position.
Pro-Physician Assisted Suicide (PAS) Interest Groups

This section contained 28 submissions made by individuals and organisations that fully support the principle of Physician Assisted Suicide and the right of the patient to die. Responses include those from the following action groups:

- Voluntary Euthanasia Society;
- Friends at the End (FATE);
- British Humanist Association (including the Humanist Society of Scotland);
- UKActNow.org;
- Lib Dems 4 Patient Choice;
- and individual members of these organisations.

All submissions in this section are in support of the proposals to allow terminally ill patients, diagnosed with 6 months or less to live, the right to choose PAS – 100% support.

The main arguments raised by this section include:

- That religion should have no place in the decisions of law. Especially as 15.5% of the population are non-religious and between 30–40% declare themselves atheists or agnostics;
- Good quality palliative care cannot meet the needs of all dying patients;
- A significant number of terminally ill patients want greater choice at the end of their lives including receiving assistance to die at a time of their choosing (73% in a study by Wilson, 2000; 80% in a study by Sullivan 1997). The fact that assisted dying remains prohibited serves to drive the practice underground, without safeguards and transparency. In such circumstances, the potential for abuse and botched suicides increases;
- Regardless of what the law says, some health professionals in exceptional circumstances appear to break it out of compassion and respect for the wishes of their terminally ill patients;
- Currently, terminally ill people whose suffering is unbearable may with or without the help of a loved one, attempt to end their own lives sometimes with deeply distressing consequences, not just for the patient but also the relative. In an NOP survey conducted in September 2004, 50% of the public were willing to break the law in such circumstances;
• An increasing number of dying patients are seeking help to die abroad from a Swiss based organisation called DIGNITAS. This organisation works without stringent safeguards and guidelines;

• Evidence from Oregon and the Netherlands shows that fears of the slippery slope have not materialised. Further, such evidence shows that it is far better to provide for medically assisted suicide within a properly regulated, open and transparent system;

• The Bill draws on the experience of Oregon in particular but it has been adapted for the UK health service. The Bill would not only deliver patient choice but also help to take the fear out of dying and the dying process;

• There are many more safeguards in the Bill than in any other end of life medical practice. When coupled with guidelines by the BMA and GMC, the Bill would be effective in protecting the vulnerable groups within our community;

• There was unanimous agreement amongst the House of Lords Select Committee that the acceptability of assisted suicide or voluntary euthanasia is an issue for society to decide;

• It is clear that the vast majority of society (including elderly and disabled populations) support a change in the law. This public attitude, alongside a growing recognition of the importance of patient autonomy in medical decision-making and recent legal judgements, make it likely that this social trend will have increasingly important influence on this debate and;

• Over the last ten years medical opinion with regards assisted dying has moved. Many healthcare professionals now support a change in the law. This is highlighted by the Royal College of Physicians and the Academy of Medical Colleges taking a neutral (versus opposed) stance towards the Bill.
Pro-Life Interest Groups

This section contained a total of 31 submissions from individuals and organisations that fully opposed the proposed legislation. Responses include those from the following action groups:

- ALERT (Against Legalised Euthanasia – Research and Training);
- First Do No Harm;
- The ProLife Alliance and;
- The Society for the Protection of Unborn Children (SPUC)

Many of the submissions were made from individuals reiterating the SPUC submission, believed to have come from the SPUC membership newsletter.

All submissions in this section are opposed to the proposals – 100% opposed.

The main points raised in this section include:

- The right to life is inalienable – there is no right do die.
- The proposals are discriminatory as they only allow the terminally ill the right to die. Individuals would be categorised and would result in them no longer being protected by the laws that protect the whole of society.
- There is fear of a slippery slope as there would be constant pressure to widen the scope of the law.
- If a patient gives up their right to life they would also be giving up their right to autonomy
- Patient autonomy would be reduced as it places too much power in the decision making abilities of the medical profession
- It would put pressure on those patients that feel like a burden
- This legislation would result in a decline in standards of palliative care as PAS is a cheaper and easier option.
- Physician Assisted Suicide undermines the role of the doctor.

A comparison of the results from sections 7, 8 and 9 shows that there was a 49% opposition to the proposals, whilst 40% were in support and 11% neutral.
Dying with dignity consultation – analysis of responses

Support

Neutral

Oppose
Academic

Eleven submissions were categorised as Academic responses. They include responses from various university lecturers and professors and also from leading law and ethics intellects.

There were a total of 5 submissions made in support of the Bill’s proposals. They came from the following:

- a Lecturer in Law and Ethics;
- an Associate Lecturer in Philosophy at the Open University;
- a Lecturer in Law at Birmingham University;
- A Sociologist at the University of Newcastle and;
- A Professor at Birmingham University.

There were a total of 2 submissions in opposition to the Bill. They were made by a joint submission by a Lecturer of Bioethics and an Adjunct Professor in Practical Philosophy at the University of Manchester, and a Doctor at the Energy and Environment Institute at the University of Strathclyde.

Neutral submissions were made by the following 4 respondents:

- Professor Sheila A MacLean, Director of the Law and Ethics Institute at the University of Glasgow;
- Professor McKilliop, Head of the Undergraduate School of Medicine at Glasgow University;
- The School of Acute and Continuing Nursing, Napier University and;
- Mary Ford, Lecturer in Law at the University of Nottingham.
International

There were a total of 20 responses made to the consultation from outside the United Kingdom. They include respondents mainly from countries that have legislated on Physician Assisted Suicide and/or euthanasia such as Oregon, Belgium, Switzerland and the Netherlands. Responses were also received from as far away as Australia and Bermuda.

The majority of submissions were from professionals who had first hand experience of the operation of Physician-Assisted Suicide and/or euthanasia legislation. They included the following:

- A Dutch Surgeon–Oncologist
- A Dutch GP and Consultant to the Dutch Court on Euthanasia
- Two Dutch GPs and SCEN-physicians (Support and Consultation on Euthanasia in the Netherlands)
- The Ombudsman and Director of the Oregon Health Services University Department of Patient Relations
- Staff of EXIT ADMD in Switzerland
- EUROSUPPORT at the Prince Leopold Institute for Tropical Medicine
- The CEO of Compassion and Choices in Oregon
- The CEO of the NVVE (Dutch Right to Die)

The overall section response to the proposal laid down in the consultation was very positive with 15 of the 20 respondents in support. The remaining 5 submissions were of a neutral position and mainly from academics from the Universities of Zurich, Groningen, Boston, and Akron in Ohio. The other neutral submission was from the Ombudsman and Director of the Oregon Health Services University Department of Patient Relations. This response included the issues believed to be important in legislation on this issue.

75% of the international response was in support for this Bill. The remaining 25% were of a neutral position.
Dying with dignity consultation – analysis of responses
Individual (miscellaneous)

This was the biggest section of the consultation categories with a total 356 submissions and making up 58% of the total response to the consultation. Respondents came mainly from Scotland but also from other parts of the United Kingdom. The majority responses were registers of support or opposition. In total there were 275 submissions of support, 69 submissions of opposition and 12 submissions that remained neutral.

The level of interest from the general public suggests that the debate on Physician Assisted Suicide is welcomed, as is the highlighting of end of life issues.

The main arguments of support expressed in this section include:

- That religious affiliations should have no bearing on legislation of this kind;
- That individuals should have a personal choice when it comes to their death;
- That it is inhumane to keep someone alive when they wish to die;
- That patients should have greater choice at the end of their lives;
- That current law is inconsistent and there is a need to create a properly regulated system that would ensure safeguards are in place and protect the vulnerable from abuse;
- That animals are not expected to suffer when nearing the end of their life so humans should have the same right.

The main arguments of opposition in this section include:

- That legislation to allow Physician Assisted Suicide will create a slippery slope, or thin edge of the wedge, leading to legalised euthanasia;
Dying with dignity consultation – analysis of responses

- That no one has the right to end another person’s life;
- That more help should be given to hospice care and that this legislation will redirect palliative care resources;
- That it will undermine the doctor–patient relationship and create mistrust between them;
- That this legislation would be open to abuse and that safeguards could prove inadequate;
- That terminally ill patients would be made to feel like a burden;
- That prognosis and diagnosis are fallible;
- That this legislation goes against the Hippocratic Oath and;
- That there is no right to die and that the right to life is inalienable.