Dying with dignity
Dr Eric Rose told the BMA’s annual conference in July 2003, that long conversations with his patient John Close, who was suffering from Motor Neurone Disease had made him rethink his stance on medically assisted dying. Dr Rose told doctors at the conference that John Close had told him that he “did not want to go on living like this, he had had enough...all the professionals had a meeting and concluded that he was rational and there was nothing we could do for him to make him change his mind.” Dr Rose told the conference that John Close, who went to Dignitas in Switzerland and did receive help to die, “had opened his mind to the topic” of whether patients should have the right to choose.

The Scotsman
4 July 2003
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Debating the end of life raises a wide range of complex and sensitive issues, and challenges some people's most deeply held moral views. The recent case of 'Mrs Z', a woman who wanted to travel to Switzerland to receive help to die, and the threat of legal action against her husband if he organised the journey illustrates that debating the issue raises questions of medical ethics and personal choice. It also challenges the role of the law.

Like many families, my own has had to come to terms with relatives who have taken their own lives. My relatives were suffering unbearable pain, but the law prevented them seeking help to die from a medical professional. While we all have the right to ask for life sustaining medical treatment to be withheld or withdrawn from us if we do not want it, the law makes criminals out of those who seek to help a competent adult who wishes to die. This limitation on our rights forces some people to endure grievous and hopeless suffering against their wishes.

I acknowledge the commitment of the Scottish Executive with its investment in healthcare and the resources that are being directed towards palliative care. I want to stress my admiration for all of those, whether they are consultants, nurses, doctors, support staff, carers or others, who offer support and provide compassion and understanding at the most difficult times of patients' lives.

However, some people with a terminal illness seek greater control at these difficult times at the end of their life, and would like to have more control over the timing and circumstances of their death. For many of these patients, their suffering is not simply the result of physical pain, but of the loss of autonomy, the inability to participate in activities, the loss of bodily functions and the loss of dignity that can accompany terminal illnesses. Experience from the US state of Oregon, where medical assistance to die has been permitted since 1997, shows that even the best palliative care cannot ameliorate suffering of this sort. Oregon's assisted dying legislation gives these patients the right to choose to die with dignity.
The proposal in this consultation is intended to allow patients the right, as they see it, to die with dignity. The proposal would give a competent adult suffering from a terminal illness, who makes persistent and considered requests to die, the right to receive medical help to bring about his or her death.

Jeremy Purvis MSP
Galashiels
January 2005
Proposal

Jeremy Purvis MSP, Liberal Democrat Member of the Scottish Parliament for Tweeddale, Ettrick & Lauderdale, is inviting views on a draft proposal for a Bill in the Scottish Parliament to allow capable adults with a terminal illness to access the means to die with dignity.

This draft proposal has been lodged in the Scottish Parliament, which is the precursor to introducing legislation.

As well as focussing on the specifics of the draft proposal, the Member wishes to encourage a wider debate on end of life issues.

Responding to this consultation

You are invited to respond to this consultation paper by answering the questions set out in this paper.

Responses, which should be submitted by 15 April 2005, may be sent to:

Jeremy Purvis MSP
The Scottish Parliament
Edinburgh
EH99 1SP

Alternatively this consultation paper is available to download online at: www.jeremypurvis.org in Word (with large print version) and PDF format and through the Scottish Parliament’s website at: www.scottish.parliament.uk

Responses can be submitted electronically to: megan.dee@scottish.parliament.uk

This consultation paper can be copied and given to others who may wish to respond; alternatively further copies are available on request.

Please note:

To help inform debate on the matters covered by this paper, and in the interests of openness, the responses submitted on this consultation document will be made public.
It will be assumed that responses can be made public unless the respondent indicates that his or her response is confidential. Confidential responses will nevertheless be included in any summary or statistical analysis, which does not identify individual responses.
Background

Some patients who are terminally ill feel they are being denied the right to a dignified death. Although they have the legal right to ask for medication or treatment to be withdrawn or withheld, or that they are not resuscitated if they fall unconscious, they do not have the right to request help to die.

A debate on end of life issues raises many complex and sensitive questions of medical ethics, law, theology and philosophy.

For some a stigma still exists in taking one’s own life. For many others there is a need to clarify issues such as:

- How the law views someone who wants to respond to a request for help to die from a patient or loved one;
- “living wills” (i.e. an advance request for life prolonging treatment to be withheld or withdrawn – also known as “advance directives”); and
- The concept of patient autonomy.

A glossary is included at the end of this paper to assist the reader with the medical language and terminology used in this field.
Current law & guidance

Both the British Medical Association and the General Medical Council (the regulatory body of doctors) have prepared detailed guidance on medical ethics in areas where:

- a person is seriously ill and relies on artificial food or hydration;
- a patient requests assistance to die; or
- the patient is in a persistent vegetative state (PVS).

In Scots law there was the landmark Johnstone case in 1996. After the case, the then Lord Advocate, Lord Mackay, stated that he would not authorise the prosecution of a doctor if, acting in good faith and with authority of the Court of Session, they withdrew life sustaining treatment from a patient with the result that the patient died.

With regards to assisted suicide, currently the law in Scotland is not clear and there is continuing uncertainty about what would happen to those assisting a person to die. For example, in Scots Criminal Law (1997) the authors state:

“Suicide is not a crime in Scots law and it is therefore not a criminal offence to attempt suicide. Encouraging or assisting another to take his own life is another matter, as the sympathy which the law has for the suicide does not necessarily extend to those who facilitate suicide. There is no Scottish authority on this issue; in other jurisdictions it is not unusual to find statutory provisions which penalise the provision of any assistance to the would-be suicide.” (page 171)

Inconsistencies in the Law

Following the Johnstone case in 1996, Professor Sheila McLean, of Glasgow University’s Institute of Law and Ethics in Medicine commented:

“What our law does, therefore, is to endorse decisions which will result in the deaths of certain patients (most notably those who cannot express a preference) but not those who are competent to ask for aid in dying.”

As it stands, the law permits suicide and allows competent adults to refuse life-sustaining treatment. It also permits doctors to withhold and withdraw life-prolonging treatment that is considered ‘futile’ from patients who cannot express an opinion (for example patients in a permanent vegetative state). However, terminally ill patients who are not physically able to commit suicide and are not in a position to end their lives by refusing treatment are not entitled to ask for help to die.

Arguably, this situation is discriminatory as well as logically inconsistent.
A further paradox is that these legal procedures are regulated only by guidelines and common law. There are no statutory safeguards to prevent abuse or ensure the law is always applied appropriately. In contrast, all established and proposed assisted dying laws abroad include numerous safeguards and reporting or monitoring of conditions.
Countries that have legislated for assisted dying

In Belgium, Switzerland, Germany, France, Sweden, Finland and Oregon assisting a suicide is not an offence. The Netherlands has also legalised euthanasia.

In other countries such as Denmark and Norway, the maximum penalties for such offences have been downgraded to as little as 60 days imprisonment.

The Netherlands

The Netherlands is one of several countries where people with terminal illnesses have the choice of being able to request medical help to die.

Their laws are based on the recognition that the best way to allow individuals choice and dignity, whilst also protecting the vulnerable, is to make end-of-life decisions transparent and subject to scrutiny and safeguards.

Belgium

Belgium allows terminally ill people the choice of requesting medical help to die.

It is one of three countries to have commissioned extensive research into what happens to people at the end of life. Before assisted dying laws were passed, Belgian research found doctors were ending patients' lives without consent or request. Compared to statistics from the Netherlands, where assisted dying is regulated by legal safeguards, the Belgians found that they had almost four times more cases of 'non-voluntary euthanasia'.

Concerned about vulnerable people being at risk, the Belgian Government passed assisted dying laws in 2002.

Oregon (USA)

Oregon's Death with Dignity Act (1997) allows a terminally ill patient who is a resident of that state to obtain from their doctor a prescription for lethal medication to be self administered. It prohibits euthanasia in terms of a doctor or other person directly administering medication to end another's life.

The Death with Dignity Act became law as a result of a 'citizen's initiative' – a referendum of all voters in Oregon.
Every year the health department publishes an annual report into how the law has been working. Every report has shown the law works well – only competent terminally ill adults are being allowed this choice, and only after all alternatives including palliative care have been explored. Further, there is some evidence to suggest that end-of-life care in general has actually improved since the law was introduced, perhaps because of a more honest and open approach to death and dying. The Sixth Annual Report of the law in Oregon (March 2004) showed that since the law was introduced, 171 patients have ingested lethal medication under the Act, whilst 53,544 Oregonians have died from the same underlying diseases.

**Assisted Dying for the Terminally Ill Bill**

In January 2004 Lord Joffe introduced the Assisted Dying for the Terminally Ill Bill to the House of Lords.

A Select Committee has been established to consider the Bill in detail.

The Bill enables a competent adult who is "suffering unbearably" from a terminal illness to receive medical help to die at his or her own considered and persistent request. It provides for a doctor to administer the medication if the patient is unable to do so and it gives a person suffering from such a condition the right to receive the necessary medication to keep him free from pain.

The Select Committee is due to report early in 2005.
Main issues

Capability

It is proposed that the Bill will only apply to "capable" patients who are adults and residents of Scotland.

A definition of a capable adult can be taken from the Adults with Incapacity (Scotland) Act 2000 in terms of:

- An adult in that statute means a person who has attained the age of 16 years.

Incapable means incapable of:

- Acting; or
- Making decisions; or
- Communicating decisions; or
- Understanding decisions; or
- Retaining the memory of decisions

The Act goes on to state: "It is noted that this does not apply by reason of lack or deficiency in a faculty of communication if that lack or deficiency can be made good by human or mechanical aid."

In Oregon, if there is any doubt about the mental capability of the patient, the patient is referred to a psychiatrist.

Options for terminally ill patients

It is important to note that in Oregon and other jurisdictions there is a duty on the doctor (or multi disciplinary care team in a hospice or elsewhere) to explain any feasible alternatives when the patient requests assistance to die.

Alternatives will normally include pain relief, hospice support and other palliative care packages that are available to the patient.

World Health Organisation definition of palliative care:

- "Palliative care is an approach that improves the quality of life of patients and their families facing the problem associated with life–threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual." (For more details see glossary.)
Dying with dignity consultation

The majority of patients who request assistance to die in Oregon are already receiving palliative care within a hospice or receiving the equivalent 'at home' hospice care which is typical in the state.

**Diagnosis and Prognosis**

Death is a certainty for everyone. Diagnosis and prognosis, however, are based on probability rather than absolute certainty in the majority of cases. Some people oppose assisted dying because they fear that a prognosis or diagnosis may be mistaken, and death would therefore be premature. Logically, this argument should apply to other end-of-life procedures too. When a doctor withdraws life sustaining treatment because he believes it to be futile, he can not be absolutely certain that further treatment would not prove useful. Yet the General Medical Council guidance states:

“Life has a natural end and doctors and others caring for a patient need to recognize that the point may come in the progression of a patient’s condition where death is drawing near. In these circumstances doctors should not strive to prolong the dying process with no regard to the patient’s wishes, where known, or an up to date assessment of the benefits and burdens of treatment or non treatment.”

**Conscience**

Currently, members of the medical professions cannot be compelled to act against their own conscience. This proposal to change the law will respect this and include provision to allow for no health professional to be forced to act against their own personal conscience.

**Reporting**

In Oregon doctors must report the writing of all prescriptions to the local health authority. An annual report is published with details of interviews taken with patients requesting medical assistance to die.

The medical professions in the UK have difficulty with the question: does assisted suicide happen today, and if so in what numbers? Invariably the answers are "yes", and "we don't know."

In Scotland there is no central reporting mechanism that could answer questions on how many requests for an assisted death were made last year, or how many patients were administered a lethal dose of medicine. In addition, there exist no means of finding out about the prevalence of deaths by ‘double effect’, and there is little transparency in the reporting of very sensitive cases. This is not a satisfactory state of affairs. It is arguable that introducing a clear, transparent system of reporting assisted deaths in Scotland would remove ‘underground’ euthanasia, and would benefit society as a whole.
What is being proposed

Who the proposals will apply to

The current proposal before the Scottish Parliament largely mirrors the law in Oregon and would allow for a terminally ill patient to request medical assistance to die (to obtain from their doctor a prescription for lethal medication to be self administered) if they are:

- An adult
- A resident of Scotland
- 'Capable'
- Diagnosed with a terminal illness that will result in death within 6 months

Those who meet these requirements could receive a prescription from a doctor if the following criteria are met:

- The patient must make two verbal requests to their doctor separated by a period of time
- The patient must provide a written request to their doctor
- The doctor and another independent doctor must confirm the diagnosis and prognosis, and determine whether the patient is ‘capable’
- The doctor must inform the patient of feasible alternatives

A reporting mechanism and an annual report would be required to be published which details incidents of prescription as well as results of interviews taken with those requesting the prescription.

Doctors and the patients’ health care authorities are not compelled to participate in the Act.

Under the law in Oregon the patient’s health or life insurance cannot be affected. In Scotland this is a reserved matter and the Bill could not make insurance provision.

It is not envisaged that there would be any significant financial burdens on the NHS, public sector, any medical organisations or private organisations arising from this Bill.

Conclusion

The underlying intention of this proposal is to ensure that the patient is central to all medical treatment decisions.
This proposal is intended to allow patients the right, as they see it, to die with dignity. The proposal would give a competent adult suffering from a terminal illness who makes persistent and considered requests to die the right to receive medical help to bring about his or her death.
Questions

It would be very helpful in the development of the Bill to receive views on the proposals outlined in this consultation, and responses to the following questions would be particularly appreciated:

1. Please specify any concerns that you have with the proposal and how these could be addressed.

2. What are your views on using the definitions of adult and incapable as set out in the Adults with Incapacity (Scotland Act) 2000.

3. By whom should reporting mechanisms be administered?

4. What period, within which death is diagnosed should a patient be entitled to request assistance to die?

5. What would the financial burdens on the NHS, public sector, and medical organisations or private organisations arising from this Bill be?

6. Do you have any further comments to make?
## Glossary of terms

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<td>Artificial nutrition and hydration</td>
<td>refers specifically to those techniques for providing nutrition or hydration which are used to bypass a pathology in the swallowing process. It includes the use of nasogastric tubes, percutaneous endoscopic gastrostomy (PEG feeding) and total parenteral nutrition (Source: BMA)</td>
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<td>Assisted Suicide</td>
<td>a third party provides the means by which a person will take their own life</td>
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<td>Competence</td>
<td>possessing the capacity to make an informed decision</td>
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<td>Death with dignity</td>
<td>concept linked to perception of human worth, value of life (and by implication death), self respect, dignity and personal autonomy</td>
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<td>Double effect</td>
<td>medication administered in considerable amount to alleviate pain with knowledge that could hasten death. Sometimes referred to as Catholic Doctrine of Double Effect</td>
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<td>End of life issues</td>
<td>wider debate of options and views as to care and treatment in medical, legal and ethical context</td>
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<td>Euthanasia</td>
<td>literally ‘gentle and easy death; bringing about of this, esp., in case of incurable and painful disease’ (Source: Concise Oxford Dictionary). A third party administers medication to a person knowing it will shorten the person's life</td>
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<td>Life-prolonging treatment</td>
<td>refers to all treatment which has the potential to postpone the patient’s death and includes cardiopulmonary resuscitation, artificial ventilation, specialised treatments for particular conditions such as chemotherapy or dialysis, antibiotics when given for a potentially life-threatening infection and artificial nutrition and hydration. (Source: BMA)</td>
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<td><strong>Living Will (Advance Directive)</strong></td>
<td>a request by a competent adult for life prolonging treatment to be withheld or withdrawn</td>
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<td><strong>Medical Benefit</strong></td>
<td>health professionals have a general duty to provide treatment which benefits their patients. Benefit, in this context, has its ordinary meaning of an advantage or net gain for the patient but is broader than simply whether the treatment achieves a particular physiological goal. It includes both medical and other, less tangible, benefits. (Source: BMA)</td>
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<td><strong>Palliative care</strong></td>
<td>the World Health Organisation defines palliative care as:</td>
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<td></td>
<td>• provides relief from pain and other distressing symptoms;</td>
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<td>• affirms life and regards dying as a normal process;</td>
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<td>• intends neither to hasten or postpone death;</td>
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<td>• integrates the psychological and spiritual aspects of patient care;</td>
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<td>• offers a support system to help patients live as actively as possible until death;</td>
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<td>• offers a support system to help the family cope during the patient’s illness and in their own bereavement;</td>
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<td></td>
<td>• uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated;</td>
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<td>• will enhance quality of life, and may also positively influence the course of illness;</td>
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<td>• is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications.</td>
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<td>Patient autonomy</td>
<td>the continuing debate over the rights of the patient in determining the care and medication that they receive</td>
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<td>Physician Assisted Suicide</td>
<td>a medical practitioner (usually a doctor) provides the means by which a patient will take their own life</td>
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<td>The primary goal of medical treatment</td>
<td>the primary goal of medical treatment is to benefit the patient by restoring or maintaining the patient’s health as far as possible, maximising benefit and minimising harm. If treatment fails, or ceases, to give a net benefit to the patient (or if the patient has competently refused the treatment) that goal cannot be realised and the justification for providing the treatment is removed. Unless some other justification can be demonstrated, treatment that does not provide net benefit to the patient may, ethically and legally, be withheld or withdrawn and the goal of medicine should shift to the palliation of symptoms. (Source: BMA)</td>
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<td>Suicide</td>
<td>act of intentionally taking one’s own life</td>
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