The Committee will meet at 10.00 am in Committee Room 1.

1. **End of Life Assistance (Scotland) Bill**: The Committee will take evidence on the Bill at Stage 1 from—

   Dr Iain Brassington, Lecturer in Bioethics, School of Law, University of Manchester;

   Professor Sheila McLean, Professor of Law and Ethics in Medicine, Centre for Applied Ethics and Legal Philosophy, University of Glasgow;

   Professor Graeme Laurie, Professor of Medical Jurisprudence, School of Law, University of Edinburgh;

   Professor Calum MacKellar, Professor of Research, Scottish Council on Human Bioethics;

   and then from—

   Mark Hazelwood, Director, Scottish Partnership for Palliative Care;

   Elaine Stevens, Chair, Independent Association of Nurses in Palliative Care;

   Katrina McNamara-Goodger, Head of Policy and Practice, Association for Children's Palliative Care;

   Stephen Hutchison, Consultant Physician in Palliative Medicine, Highland Hospice;

   Dr Chris Sugden, Medical Director, St Andrew's Hospice.
The papers for this meeting are as follows—

**Agenda Item 1**

Submission from Dr Iain Brassington  
ELA/S3/10/5/1

Submission from the University of Glasgow's Centre for  
Applied Ethics and Legal Philosophy  
ELA/S3/10/5/2

Submission from Professor Graeme Laurie  
ELA/S3/10/5/3

Submission from the Scottish Council on Human Bioethics  
ELA/S3/10/5/4

Submission from the Scottish Partnership for Palliative Care  
ELA/S3/10/5/5

Submission from the Independent Association of Nurses in  
Palliative Care  
ELA/S3/10/5/6

Submission from the Association for Children’s Palliative  
Care  
ELA/S3/10/5/7

Submission from Highland Hospice  
ELA/S3/10/5/8

Submission from St Andrew’s Hospice  
ELA/S3/10/5/9
End of Life Assistance (Scotland) Bill

Dr Iain Brassington

Do you agree a person should be able to request end of life assistance from a registered medical practitioner?

The short answer to this is that I do.

The value that a person ascribes to his own life is irreducibly and overriding importance; though a person may be valuable to others, and they may prefer that he continue to live, a person’s own ascription of value to his own life is morally primary. From this, two things follow. First, that noone else has a right to take that person’s life from him without his consent (except, perhaps, in a few highly exceptional circumstances such as self-defence); second, that if he decides that his life is a burden to him and prefers that it should end, noone else has the right to prevent the end of that life.

However, it is also true that ending one’s own life may be difficult – a person may not succeed in a suicide attempt, and stands a reasonable chance of survival in a worse position than he found himself before the attempt. It is also entirely possible that a person would find suicide problematic because of the fact that the burden of finding his body would fall on others (the alternative being that another person would be asked to “stand guard” while the suicide happened, which would currently be both legally problematic and quite possibly unreasonably morally burdensome); he might well prefer his desired death to happen in circumstances affording the highest level of control. Moreover, of course, the ability to kill oneself is merely formal in respect of those whose medical condition is such as to incapacitate them in some way: the current state of the law is not exactly discriminatory towards the disabled (since they do have exactly the same rights as the able-bodied in respect of self-killing – they just find it harder to capitalise on them), but it does place them in a situation of “double jeopardy”, whereby the exercise of those rights is hampered by their condition when that condition is plausibly a contributing factor to their wanting to end their own lives to begin with.

Nor is it clear why a person, motivated by humane considerations, ought not to be allowed to assist a person in the project of ending his own life, granted the supposition that ending his own life is genuinely what that person wants. For this reason, if a person wishes to end his life, and if he is unable or unwilling to set about this task on his own, he ought to be able to seek assistance.

It does not follow from this that he ought always to be provided with assistance – that a person has formulated a certain desire does not indicate that anyone is obliged to help him realise it. That I wish to be shot from a circus cannon does not imply that you have to lend me yours; that I want my broken arm treated with antibiotics does not imply that the NHS ought to provide them to me; and the same principle applies here. If noone is available or willing to assist a person in bringing about his own death, then he has no
moral right to compel assistance; nor ought he to have the legal right. Hence the right to assistance takes the form of a permit rather than an entitlement.

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

The age requirements are potentially problematic. I take it as read that laws have to be workable, and that this means that there are requirements for them to be as simple as possible. Therefore an attempt to draw a “bright line” in respect of age restrictions is perfectly understandable.

However, there are potential objections to placing an age limit at 16. One of these is easily dismissed; the other is not so straightforward.

The easy problem is this: that there may be a child under the age of 16 who satisfies the demands of *Gillick* competence, and who would, in normal circumstances, be considered competent. Why should assisted dying be denied to her? Yet two responses can be made here. The first is that competence tests refer to consent, rather than requests. Since a patient would not – one can assume – be consenting to a medic’s suggestion of assisted dying, appeals to consent seem to be *de trop*. The second is that, if assisted dying is available as a matter of permit rather than entitlement, it is in the gift of the legislature to allow it or forbid it to whomsoever it pleases.

However, this leads to a more difficult problem. If we accept that a person has the moral right to seek assistance in bringing about their own deaths, and that another person has the moral right to provide it, and if we accept that these moral rights ought to be reflected in law, it is not immediately obvious why there should be a lower age barrier imposed. To insist that Smith has fewer (legal) rights than Jones simply on the basis that Smith is younger looks to be ageist: it makes age do the work of a morally relevant consideration when it is not clear, exactly, what the relevance of age is. It might be that age is felt to be important because of worries about establishing maturity – but, in this case, it is not clear why the specification in the law could not refer directly to a maturity test of some sort. That is to say: if maturity is what matters, then the law should say so. (I have already noted that the right to provide assistance does not imply a duty to provide it, so any maturity test could be quite demanding, on the assumption that refusing assistance to die to someone who actually is sufficiently mature is preferable to providing it to someone who is not.) Appeals to age on this basis would risk depriving some people of their entitlements without justification.

*mutatis mutandis*, the same worries would apply should age be treated as a cipher for any other consideration. In all cases, it’s hard to see why mere chronological age is different from sex or ethnicity; and since we would not think of restricting access to something like end of life assistance to someone based on appeals to sex or ethnicity, it’s not obvious why we think we can restrict access based on appeals to age.
Agenda Item 1
14 September 2010

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

No. Sections 4(2)(a) and 4(2)(b) are too restrictive. They represent an improvement on the terminal illness and unbearable suffering criteria articulated in Lord Joffe’s Assisted Dying for the Terminally Ill Bill, but, in the end, they are vulnerable to the same objections.

The first of these is that it is simply not obvious why a person should have to be ill, incapacitated, or suffering at all to make use of end of life assistance. We may not see why a person who is not would want to die, but that is not enough to tell us that there could be no such person; and if someone does want end of life assistance for what seems to us like a trivial reason, then this is up to him. (Again, we do not have a duty to assist; but we could still have the right.) Indeed, granted the reasonable assumption that most people would strongly prefer not to die, then the more unexpected their preference, the stronger the evidence that it is genuinely held. After all, someone suffering from a terminal illness may be more vulnerable to pressure from others to seek assistance; it’s hard to see why a healthy person would succumb to such pressure, though – so this generates the conclusion that the likelihood of any healthy person seeking end of life assistance due to external pressure is minimal.

More importantly, the criteria given seem inhumane, inasmuch as they force people to live an intolerable life for at least a period. It may be, for example, that a person has been diagnosed with an illness that he expects to cause him great suffering at some point in the future, and wishes to avoid ever reaching that point. We might expect a person to prefer a life that never becomes intolerable; if I have a reasonable expectation that my life will become intolerable, I may therefore feel that I have a reason to end it now – to deny this would be a bit like saying that the gambler cannot leave the card table until he is utterly destitute. It is perplexing to think that the law may require a person’s life to become intolerable before offering him the opportunity of assistance to end it.

Nor will it do to say that the certainty of future hardship is itself sufficient to make a life intolerable: there is nothing incoherent about a person who prefers to end his life before its quality falls, notwithstanding that that life is at the moment perfectly acceptable; and while the prospect of future suffering may be an intolerable stain in an otherwise good life, this kind of dread is not what the bill specifies – it refers exclusively to the life itself being intolerable. (I assume, though section 4(2) is unclear, that the intolerability is meant in the wording of the bill to derive from the illness or incapacity in question.)

The very notion of intolerability is also unclear. By what standard is intolerability to me measured? Presumably, it is more than a mere preference – even a strong preference – that something not happen. Yet just about any misfortune is, in the strictest sense, tolerable, inasmuch as that we could imagine some sufficiently strong-willed character tolerating it; therefore if we are to be literal in our interpretation of the intolerability criterion, noone would
be entitled to assistance. Moving away from it, though, makes any restriction seem arbitrary.

Similar concerns apply to the terminal illness and to the incapacity and dependence considerations: it seems arbitrary to restrict assistance in dying to those whose wish for assistance may be wholly in earnest, but who happen not to have the “right” kind of medical problem. The only difference between a terminally ill person and a chronically ill person is the length of their counterfactual survival were they not to seek end of life assistance. But if a person is sovereign over her own life, it’s hard to see why this expected survival time ought to make a difference to the policy. It therefore looks as though assistance should be available to the chronically ill. But, if one is willing to make this move, then it becomes hard to see why assistance should be denied to the non-chronically ill, or to the ill at all. And this is perfectly compatible with the guiding thought that the final say over the continuation of a life properly resides with the person living it.

Incapacity, furthermore, is not obviously important here, just because we might imagine a person who is perfectly able-bodied but who wants assistance to ensure that her death is as certain as possible. Or we might imagine another person who is moderately disabled by a road accident and who is not incapacitated in any particularly strong sense, but who finds his sudden inability to play the violin a crushing loss; such a person would not be incapacitated in the everyday sense of the world, but he may find that the thing that gave his life its meaning has been taken from him.

Of course, it may be true that, given time, a person would come to terms with his situation. However, to insist on this is to adopt a highly patronising view of the would-be dead person: it amounts to the idea that he is not the best person to make decisions about his continued existence after all.

For elaboration of these worries, see I Brassington, “Five Words for Assisted Dying”, Law and Philosophy 27(5), 2008, pp 415-444.

The Bill outlines a two-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?

Yes. A “cooling off” period would seem to be reasonable to ensure certainty.

Do you consider the level and nature of safeguards as set out in the Bill to be appropriate?
Yes, subject to the provisos above.

Do you have any other considerations on the Bill not included in answers to the above questions?
No.

Dr Iain Brassington
13 April 2010
I should say at the outset that I welcome the opportunity for Members of the Scottish Parliament to debate this important issue, and for members of the public to make their own views known. I have confined myself in what follows to addressing specific matters in the Bill itself, but would be happy to supply further information on the general area if that was deemed appropriate.

s. 2(1)(b): arguably, this gives an excessive amount of power to doctors, and may allow them to impose their own morality in deciding whether or not to allow the patient’s request. Giving this supreme gate-keeping role to doctors risks the kind of problems that arose initially in the interpretation of the Abortion Act 1967, which ultimately required that doctors were instructed by their professional bodies that they must refer to another doctor if their own morality was opposed to abortion. Perhaps the obligation to refer for a second opinion in such cases should be written into the Bill to avoid these problems arising. This would allow doctors to act according to their conscience, without precluding patients from accessing an assisted death. Perhaps this could be achieved by the inclusion of a ‘conscience clause’ which includes the specific requirement to refer on.

s.4(2)(b): I think that there could be serious problems surrounding the interpretation of what amounts to ‘independent living’. Again, given the authority handed to doctors by this Bill, this is presumably open to interpretation which could be based on personal attitudes. ‘Independent living’ does not seem to be susceptible of objective analysis. That being so, it might be preferable to omit this criterion altogether and simple rely on the individual’s belief that life is ‘intolerable’.

s. 6(1)(b): I think that a ‘valid and documented request’ should be broadly described; that is, it can be verbal or in writing, but must be properly recorded by the attending clinical staff. If patients are unable to sign a document, a witnessed verbal declaration, signed by witnesses and the attending physician should be sufficient evidence of intent. Otherwise, some people with particular kinds of disability would be unable to take advantage of the law. It should be noted that one of the major initial challenges to the Oregon Death with Dignity Act came from the disabled lobby who argued that some disabled people would be unable to avail themselves of the Act because of an inability to swallow the prescribed medicine. Similar objections could be raised to the need for requests to be in writing.

s.9(4): It might be worth specifically noting here that the mere presence of a mental illness does not necessarily (in law) mean that a person lacks competence. The definition of competence in this section seems to have been lifted more or less completely from the (English) case of Re C, in which
the court upheld the right of a man suffering from paranoid schizophrenia to refuse treatment that, in the view of his doctors, would be life-saving. Problematically, the explanatory notes to the Bill seem to go against this generally accepted proposition by specifically indicating that the term ‘mental disorder’, the existence of which would presumably preclude the individual from making a valid request for assistance, includes ‘mental illness’.

s.11(2): there is no obvious rationale for the request’s validity to expire after 28 days. Evidence from Oregon suggests that a number of people have chosen not to use the prescription for some time after it has been provided – in some cases this has been more than a year. The evidence suggests that some people are comforted by the mere knowledge that they can end their life at a time of their choosing and may in fact live longer than if they were forced to take the medicine within a specified time limit. While it could be argued that this section doesn’t prevent people from re-starting the process, it seems an unnecessary restriction. The process is already complicated and this additional requirement may act as a disincentive for those who otherwise satisfy the necessary conditions to make further attempts. It is difficult to identify what harm would be prevented by this requirement.

In the explanatory notes to the Bill, it is said that article 11(6) requires the designated practitioner to be present ‘when end of life occurs.’ In general, I am unclear why this requirement is in the Bill, but specifically, the question must be answered as to what would happen if the ‘designated practitioner’ is incapacitated, or dies, or is otherwise unable to be present? Is it intended that the qualified patient’s right to receive an assisted death can be invalidated merely because of the unavailability of a third party?

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12 April 2010
Introduction

This brief paper offers commentary on the January 2010 Bill put before the Scottish Parliament. The objective is to raise points for discussion or of concern with respect to the drafting of the Bill before it comes before the Scottish Parliament. The fact that we have contributed to the consultation should not be construed as evidence that either or both of us approves or disapproves of either assisted suicide or euthanasia; that is a broader and distinct question which we believe requires a different approach from that adopted in the present consultation. Further, while the views expressed herein reflect our agreed personal opinions, they do not necessarily reflect any wider views or opinions of colleagues in the Law School or University.

Comments on specific provisions

S.1. We note the emphasis in this section and throughout the Bill to a ‘person’ who provides assistance in dying. The implication, backed by s.11(6) of the Bill, is that there is no requirement that a medically qualified practitioner carry out the final act of assistance. So far as we know, this is the first Bill in the UK that has attempted to go beyond physician assisted suicide (PAS).

There are two major consequences:

- a) It means the Bill will almost certainly fail;
- b) It has to be accepted that this is not just an extension of the Oregon legislation or Lord Joffe’s Bill presented in the House of Lords but represents largely uncharted territory for any jurisdiction.\(^1\) As such, it is a leap into the unknown and has to be treated with exceptional care.

S.1(2) We believe the sub section to be seriously flawed in that it defines assistance as ‘including the provision or administration of appropriate means’. At the very least, this implies that the two procedures are to be morally and legally interchangeable without further ado. In fact, it is almost universally held that assisted suicide and euthanasia are distinguished by the fact that assistance in dying is provided in the former and administered in the latter. The breadth of the Bill is, thus, extended even further than appears on the surface in that it legalises euthanasia ab initio. It is imperative that this is made clear rather than having to be sought within the text.

\(^1\) We draw attention to the position under Swiss law where, as we understand, it is not a criminal offence for a person to assist another in dying so long as the motive is altruistic. For comment see O Guillod and A Schmidt, ‘Assisted Suicide under Swiss Law’ (2005) 12(1) European Journal of Health Law 25. A copy can be provided on request.
While we believe that this is far more than the public – or parliament – is likely to accept, we suggest that, at a minimum, s.1(2) is amended along the lines:

‘In this Act, end of life assistance includes:

a) the provision of appropriate means or
b) in the event of the requesting person being physically unable to utilise such means, the administration of appropriate means so as to enable ....’

This, in our view, would serve to limit potential distortion of the Bill’s intentions – say, into the field of mercy killing – but would, simultaneously, address one of the most difficult problems in the area – that is, the management of the patient with incapacitating neuromuscular disease.

In respect of the final line of s.1(2), we caution against the inclusion of the terminology of ‘die with dignity’ in this Bill or any subsequent Act. There are two reasons for this. First, the expression ‘dignity’ is notoriously difficult to define and could lead to considerable legal uncertainty. It adds little or nothing to the Bill as it stands. Second, if the reference to ‘dignity’ is a synonym for respecting an individual’s choice to die then it is unnecessary and redundant given the general thrust of the Bill. If a broader notion of dignity is intended then this could be open to wide-ranging interpretation and confusion. We suggest it is sufficient to say: ‘.... enable a person to end his or her life in accordance with ss. 4 and 11 below.’

S. 2. The section refers to ‘medical practitioner’ but there are two minor concerns with this:

a) There is no mention of experience;
b) The law will shortly require that registered medical practitioners must also be licensed if they are engaged in patient care.

We suggest alternative wording: “Registered medical practitioner of at least five years’ standing and holding a current licence to practise.”

S. 3. We believe that consideration should be given to the possibility that temporary and valid revocation can be given to someone other than the designated practitioner in the event that the designated practitioner is not available. We appreciate that s/he must be present at the ultimate act of assistance but they may not be available at an earlier point in time when the patient might wish to revoke their request for assistance. On a practical point, what happens if the practitioner dies or is otherwise indisposed? Is there a case for a nominated deputy in the event that the practitioner becomes incapacitated?

S.4. ss.1(a) Scots law has a tradition of protecting children up to and beyond the age of 16 from decisions that are manifestly against their interests. Thus, for example, while a child has capacity to enter a contract between 16 and 18, this is can be struck down up to the age of 21 if it is
shown to be against his or her interests. Similarly, while the law provides that a child under 16 who understands a medical treatment can give valid consent to that treatment, it does not provide for an automatic right to refuse treatment. Although the arguments are balanced finely on both sides around the need to respect and protect the evolving capacity of the child, it is clearly the case that Scots law can and does intervene to protect children from harmful decisions. On this basis, we suggest that there are strong reasons to argue that the Bill should only apply to those of 18 and over.\(^2\)

If we are to deviate from the threshold of 18 then we suggest that it would be consistent to reflect the concept of understanding as per the Age of Legal Capacity (S) Act 1991, s.2(4). The difficulty here is how anyone can possibly understand death since no-one can tell us what it involves.\(^3\) This having been said, it is, we admit, not an issue that has prevented other jurisdictions adopting legislation on assisted dying. As a final point, and inconsistent though it may be, if the recommendation is to follow the approach of the 1991 Act then it might be prudent to incorporate a minimum age – e.g. 14 - below which authorisation was impossible as a further protective measure for minors.

ss.2(b) We suggest the desirability of a firm rider here on the following lines:
‘The fact that one’s financial resources were, as a result, being compromised would not be allowed as a measure of intolerability.’

ss.(3) We question the inclusion of a restricted 6-month window of opportunity before death if the test is indeed to be intolerability. Surely the real concern is for those who are suffering over the longer-term and who wish to end their pain or other measure of intolerability. We suggest that the reference be to “progressive, fatal condition which cannot be halted”. If the concern is to build in some form of protection mechanism to avoid abuse or expanded use of end of life assistance, then we would point to s.9(2) which requires that full discussions be undertaken about alternative options including palliative care.

For various reasons, mainly semantic, we further suggest that the concept of ‘unbearable suffering’ should replace ‘intolerability’ on the grounds that something that is intolerable, cannot, by definition, be tolerated whereas ‘unbearable suffering’ more accurately reflects the subjective experience of the patient and his/her choice to end that suffering. Note that the appellate English courts have consistently questioned the value of the concept of ‘intolerability’ in cases involving withholding/withdrawal of care.\(^4\)

S. 5(2)(a) Mainly for the avoidance of doubt, we believe that this provision should read ‘only if that person or the requesting person knows of ..’

\(^2\) When adulthood is attained: Age of Majority (Scotland) Act 1969, s.1(1).

\(^3\) For judicial recognition of this problem, albeit in a different context, see McKay v Essex AHA [1982] 2 All ER 771, Court of Appeal.

S. 6(1) There is considerable controversy over how long an advance decision should remain in force due to changes of circumstances etc. Any comparable concern over time in respect of assisted dying should be mollified, however, by s.11(2), (3) which make it clear that assistance must be provided before the expiry of 28 days from the notification of the approval of the second request. Any remaining doubt centres on how long a request can remain valid before the designated practitioner takes action and this is not clear from s.2. It is to be noted that the time bar relates only to the time between the approval of the second formal request and the provision of assistance in dying (s.11(2)).

A further issue relating to this 28 day time factor is the question of the need for a cooling-off period. If a patient changes his or her mind at the last minute must they begin the process all over again or could the law allow an extension of this period? Such a provision could help to avoid charges of coercion. Equally, returning to our first point, this period should not be too long lest it undermine the original decision. We propose that a one-off extension of 28 days, overseen by the designated practitioner and the psychiatrist, should be included.

S. 9 What is to be the definition of a ‘psychiatrist’ for the purposes of the Act? Presumably this would be a registered medical practitioner who is registered as a psychiatrist in the GMC’s specialist register. Even so, there are different types of psychiatrist just as there are different types of pathologist and there is no mention of experience. This is such an important area that it seems to us that there must be very firm evidence of expertise in the field. We suggest something like:

For the purposes of the Act, a psychiatrist is a registered medical practitioner having a current licence to practise who has (a) been registered as a psychiatrist in the GMC’s specialist register for at least 5 years and (b) is certified by the Scottish Ministers as having particular expertise in the field of suicide and assistance in dying.

S. 9(4) A central question in this area of legal reform relates to how given the very wide definition of mental disorder provided by the 2003 Act, a person who is suffering such pain that life is intolerable is not, as a consequence, suffering from a mental disorder which might affect the making of a request under the Act? However, this is a problem that crops up throughout the euthanasia debate and it has not proved to be insurmountable in other jurisdictions. What is important is that it opens up the possibility of considerable subjectivity on the part of psychiatrists and this is of major importance in view of the free movement of doctors in the EU. You could get a very different answer to a request for assistance from a Dutch rather than a Scottish psychiatrist - but our recommendation above as to definition might address this concern adequately.

S. 9(6) Closer to home, we question very strongly the wisdom of the inclusion of this provision which states that ‘the psychiatrist who acts in relation to the second formal request need not be the psychiatrist who acted in relation to
the first formal request’. The purpose of this is unclear. It could easily lead to the difficult situation where the two psychiatrists disagree. What is to happen then? How will disputes be resolved and where does this leave the requesting person? If it is some form of protective mechanism then we suggest it should be a requirement that two separate psychiatrists be involved. If two are to be involved then some dispute resolution mechanism is required as an integral part of the Bill.

S.10 We think it very important to include the following additional provision as sub sec 10(1)(e):

(e) who is to be present at the time the assistance is provided, with the proviso that the nominations are solely at the discretion of the requesting person.

In this respect, for the avoidance of doubt, we suggest an addition to s.11:

Sub sec 11(7). The fact that a person has or may have a pecuniary or other material interest in the death of the requesting person will not prohibit his or her nomination under s.10(1)(e).

Absent such a provision, the propriety of the presence of close relatives, who might well figure in the requesting person’s will, might be questioned

S.11(6) This provision takes us back to our comments at the very beginning of this paper: arguably the most disturbing part of the Bill is that it confirms that we are dealing with more than PAS. Not only does it extend assisted suicide to euthanasia but it also reduces the role of the doctor almost to that of counsellor – the only medical requirement as to the actual assistance is that a medical practitioner must be present when the deed is done. Is the Bill deliberately setting up a trade of euthanasist? This may, of course, be a good thing insofar as it might satisfy those doctors who have a conscientious objection to ending life. Nonetheless, there are many members of the public who would see this as an unacceptable extension of PAS and the preamble to the actual assistance involves the doctor to such an extent that it is a remarkable conscience that would be happy to go through the complex administrative process but would feel salved by not actually delivering the fatal dose. We can see tenable arguments on both sides:

In favour of the role of the euthanasist
- This sends a clear message that active assistance in dying by way of assisted suicide is not the proper role of the medical profession
- This might remove opposition from the medical profession on both ethical and professional grounds
- There is some precedent for this non-medical role from the experience of Switzerland; if the Bill were to succeed, the position in Scotland might be an improvement in respect of safeguards in that, at least, a medical practitioner would have to be present.

Against the role of the euthanasist
Who would be trained to take on this role? What qualification would be required and how would it be policed?

Will the removal of the medical profession from the final act undermine trust in the legislation?

Does this blur the distinction between mercy killing and assisted suicide to an unacceptable degree?

Finally, since the explanatory notes refer specifically to trauma as a possible eligibility requirement (at para 22), we wonder whether the Bill should contain a disclaimer along the lines: ‘The application of s.1 of this Act will represent a novus actus interveniens for the purposes of the criminal law relating to homicide.’ We confess to being divided on this point. One of us believes that assistance in dying should normally be considered as a new intervening act that breaks any causal link of liability for the person who brought about the original trauma. The counter argument is along the lines that a person whose criminal activity has been such as to render a person’s life intolerable should not escape the consequences if the victim bows to the intolerability of the situation into which he or she has been forced. A possible compromise is to consider whether there should be a rebuttable presumption that the casual chain will be broken by assistance in dying and that this can be overturned by prosecution services on good grounds shown.

Professors GT Laurie and JK Mason
School of Law, University of Edinburgh
21 April 2010
End of Life Assistance (Scotland) Bill

Scottish Council on Human Bioethics (SCHB)

The Scottish Council on Human Bioethics (SCHB) is an independent, non-partisan, non-religious registered Scottish charity composed of doctors, lawyers, biomedical scientists, ethicists and other professionals from disciplines associated with medical ethics.

The principles to which the SCHB subscribe are set out in the United Nations Universal Declaration of Human Rights (1948).

Question 1: Do you agree a person should be able to request end of life assistance from a registered medical practitioner?

The SCHB considers that both euthanasia and assisted suicide are dangerous and unnecessary. This is because:

1. Euthanasia and assisted suicide would undermine the protection due to the most vulnerable persons in society

Legalising euthanasia and assisted suicide is dangerous because vulnerable people may begin to consider death as a possible option for releasing family members, carers and the broader society from the responsibility of providing support. These vulnerable people, such as the elderly, may then believe that their death is a greater good and that they have a duty to pursue euthanasia or assisted suicide.

Vulnerable people need to know that they are valued and unconditionally accepted by the community. They need to know that society is committed first and foremost to their well-being, even if this does involve expenditure of time and money. Indeed, the manner in which the weakest and most vulnerable members of society are treated reflects the true identity of a society because it reveals its core values.

2. Euthanasia and assisted suicide would undermine the relationships of health care professionals with their patients

While all admit the inevitability of death, intentionally and actively pursuing the death of a patient, fundamentally changes the role of the physician, changes the doctor-patient relationship and changes the role of medicine in society. Moreover, physicians alone are not qualified to make quality of life decisions.

Some physicians may also become hardened to death and to causing death, particularly when patients are old, terminally ill, or disabled. Legalising euthanasia would give persons, such as physicians, power that could be too easily abused, and a responsibility that they should not be permitted to have.
In very rare cases, physicians such as Harold Shipman\(^1\), may actually feel empowered in being able to provoke death and escape prosecution because of the evidential problems which would arise in this Bill.

In the light of these cases, many vulnerable groups of people and their families may begin to mistrust the real intentions of their doctors.

Historical precedent in the Netherlands demonstrates that progression to involuntary euthanasia requires only four accelerating factors: favourable public opinion, a handful of willing physicians, economic pressure and no convictions for those involved. If legislation allowing euthanasia comes into effect, and political and economic interests are brought to bear, the generated momentum could prove overwhelming.

3. Palliative care can address the suffering of a terminally ill person

Physical suffering can be adequately alleviated in all but the rarest of cases with up to 95% of patients having their pain and/or symptoms effectively relieved when treated by healthcare professionals with the relevant expertise\(^2,3\).

In addition, the administration of short episodes of sedative drugs can be considered as an appropriate alternative to manage distress and restlessness of persons facing imminent death. This can happen when patients are often barely conscious as a result of their disease (not because of the drugs) and are no longer capable of consciously working through their issues. In this case, palliative care helps patients (and sometimes also their families) by calming their terminal agitation.

Usually, the treatment is a matter of gradually increasing the level of drugs according to effect. However, there are occasions when a patient is very agitated and rapid use of large doses of drugs is essential for the safety and comfort of the patient and others.

Nonetheless, there will always be rare occasions where a patient’s symptoms cannot be completely controlled. Often these are patients who cannot resolve an issue or cannot cope with a symptom, such as with severe breathlessness. Some may also have significant psychological and/or spiritual distress which they find difficult to resolve. Indeed, almost all patients with symptoms which cannot be completely controlled have elements of this distress which is not recognised as physical.


\(^2\) Organisations such as the Hospice Movement reveal that suffering can be adequately alleviated in all but the rarest cases. See also Pain Control - BBC - http://www.bbc.co.uk/religion/ethics/euthanasia/euth_pain_control.shtml; Using Opioids to Control Pain, http://www.painlaw.org/opioids.html

\(^3\) When correctly used to relieve pain in a patient who is terminally ill, morphine should never cause death. By contrast it usually lengthens life and improves its quality. This is because the therapeutic dose of morphine, which relieves pain, is virtually always well below the toxic dose which ends life and because the relief from pain which it brings removes stress factors in the patient’s condition.
These individuals, who are already drowsy and dying of their illness, may then request some form of sedation to relieve the burden of such suffering, in which case it may be possible to manage their distress and agitation without side effects. In other words, drugs are administered and monitored to induce a state of decreased or absent awareness (unconsciousness) in order to increase comfort in the dying process rather than, in any way, shortening life\(^4\).

It is very unusual for palliative care to have to use continuous sedation to keep a lucid patient asleep in order to address intolerable physical and/or mental distress. Indeed, sedating people deliberately to deal with their suffering is a very rare occurrence in the UK.

Of course, it is important that patients with difficult symptoms are not promised complete relief since this is beyond the realm of medicine. In this regard, it should be noted that palliative care does not only seek to work in the area of medicine since it also endeavours to provide non-clinical support and the right environment for patients to express and work through their distress. Thus, few patients request euthanasia or assisted suicide when their physical, emotional and spiritual needs have been adequately addressed.

4. Euthanasia and assisted suicide should not be considered as a medical procedure

Euthanasia and assisted suicide undermine the traditional goal of medicine, namely to cure and care but not to harm or kill patients.

Moreover, research demonstrates that most sustained demands for euthanasia are actually considered by persons suffering from existential problems or because they have an extreme concept of control and independence\(^5\). In other words, the argument in favour of euthanasia is more about control than medicine.

5. It is wrong to suggest that any person can ever lose his or her intrinsic human dignity

Advocates of euthanasia or assisted suicide suggest that individuals should be able to determine their own dignity and quality of life, unrestricted by the moral, cultural, religious, or personal beliefs of others. For example, it has been proposed that persons who fear that they will lose their dignity during the final stages of a terminal illness should be able to 'die with dignity' before these stages occur.

\textit{In response to this, the SCHB notes that:}

\[^4\] Nathan I Cherny, Sedation for the care of patients with advanced cancer, Nature Reviews Clinical Oncology 3, 492-500 (September 2006).

It is incorrect and disturbing to suggest that any person can ever lose his or her human dignity. Though human dignity is not a scientific concept, it is something that everyone should always accept is found in every person to an equal extent. This is in accordance with the United Nations’ Universal Declaration of Human Rights which affirms in its preamble “the inherent dignity and…the equal and inalienable rights of all members of the human family” as “the foundation of freedom, justice and peace in the world”.

At present, we live in a society where human dignity is universal, equal and inherent. However, legalising euthanasia would mean that society would accept that some individuals can actually lose their inherent human dignity and have lives which no longer have any worth, meaning or value.

It would also mean denying the human dignity which is due to an individual, in order for him or her to be legally killed. In other words, it would give the message that human dignity is only based on subjective choices and decisions and whether a life meets certain quality standards.

In this regard, it should be noted that a society that no longer believes in the inherent dignity of human life cannot offer any valid argument against the taking of life of others, who may be considered unworthy of human dignity. It becomes a society that has lost its trust in the intrinsic value and meaning of life and cannot comprehend why it should be endured.

This is in complete opposition to a responsible benevolent and compassionate society which continues to affirm and defend the lives of all its members and the notion that every human life is full of value, meaning and richness even though persons may be aged, dependent on others or may have lost their autonomy. Therefore, in order to function consistently, society must reject the option of euthanasia if it does not want to undermine basic societal and fundamental values.

6. Full and complete autonomy undermines the concept of human dignity

Advocates of euthanasia suggest that a person’s fear of disability and dependency should enable him or her to die while he or she is still autonomous and that euthanasia would enable self-determination to exist. In other words, individuals have the right to take decisions concerning their own life and death situations in accordance with their own values and beliefs. These should not be imposed by a court, a physician or a family member. Thus, advocates of euthanasia suggest that nobody has the right to impose on the terminally-ill and the dying an obligation to live out their lives when they themselves have persistently expressed the wish to die.

In response to this, the SCHB notes that:

The recognition of every individual’s full, complete and total autonomy is antithetical to the concept of human dignity and to the proper functioning of an interactive society. Accepting such an extreme form of autonomy would mean
the atomisation of each human being whereby every person would live as a completely free and independent individual. Society, as such, would then cease to exist.

Indeed, the very concept of human dignity is dependent on persons having relationships with one another in an interactive society. It is not based on an individual’s own limited personal subjective views of himself or herself. In this respect, it should be noted that it is only because society believes in the human dignity of persons, that it respects their autonomy.

Moreover, being dependent on others should never be associated with a loss of dignity. All are born dependent on others, and many will die dependent on others. Being dependent on others at different times in a person’s life is a basic characteristic of human existence.

In addition, the legalisation of euthanasia and assisted suicide may undermine the autonomy and impose a level of coercion on medical and other health care practitioners or individuals. They may, indeed, feel obliged to carry out an act of euthanasia against their wishes or personal beliefs.

7. Human dignity is grounded on an interdependent society

Some supporters of euthanasia argue that persons should be able to decide, for themselves, whether or not they have lost their dignity and that this decision does not have any consequence for other members of society.

In response to this, the SCHB notes that:

In an interactive society, making a choice about the value of a life (even one’s own) means making a decision about the value of other lives.

In other words, persons who consider that their lives are no longer worth living or that they have lost their dignity imply that the lives of persons in similar (or worse) medical situations are also not worth living and should be ended. A right to die may then become a duty to die (see comment 1.).

Similarly, persons who believe that their lives are no longer worth living or that they have lost their dignity must also reject the worth, value and meaning that others, such as their family, friends and even society, are giving to their lives. But to consciously deny and reject the value, meaning and worth given by others to our lives, without attenuating circumstances such as a psychological disorder, means putting oneself at the centre of all that matters. Moreover, to reject the intrinsic dignity that another person is seeking to give to our lives represents a denial of this other person’s capacity to confer dignity which is tantamount to rejecting him or her as a person.

Thus, personal opinions about worth, meaning and value of human life matter to the whole of society.
8. Neither suicide nor euthanasia should be seen as acceptable alternatives

The attempted suicide of an individual, such as a young person, is never seen as something to be encouraged in society. Instead, great concern is raised regarding the individual’s state of mind and the fact that he or she may need psychological assistance or counselling. In other words, it would be completely unethical to help someone commit suicide in these circumstances. In the light of this, it is difficult to consider how any form of assisted suicide can be considered.

Conversely, if assisted suicide were decriminalised, a risk would then arise that the suicide of individuals, such as healthy young persons, would also be considered as acceptable to society at the very moment when the Scottish government is trying to reduce the very high suicide rates in some parts of the country with programmes such as ChooseLife (www.chooselife.net).

Moreover, with euthanasia or assisted suicide, as opposed to suicide, another person must believe that it would be preferable for the person wishing to die not to continue living. In other words, euthanasia and assisted suicide, reflect the unacceptable belief by one person that another person has lost, or can lose, his or her dignity to such an extent that his or her life is not worth living and should be ended.

When society acknowledges the acceptability of one person being willingly involved in the death of another person, dangerous consequences as to the manner in which the whole of society considers the value, meaning and worth of human life are to be expected.

9. The request to die may not reflect the patient’s real wishes

Generally, experience shows that once people receive palliative care and are comfortable, with their fears concerning suffering being addressed, they often change their minds about wanting to end their lives.6

There is also good evidence that a desire for death in terminally ill patients can vary with time and is closely associated with clinical depression which can often be treated.7 States of delirium and/or confusion are common in palliative care patients and are sometimes so subtle that they are difficult even for clinicians to recognise. It is impossible to be absolutely confident that a request for a life to be ended does not arise from a disordered state of mind.

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In other words, whilst many people are competent to make decisions about their wish for euthanasia and assisted suicide, many are not. This opens the possibility that a decision to end a person’s life could be made by a second person such as a nominated proxy. The complexities arising from such conditions could lead to a serious abuse of power.

**Question 2:** Are you satisfied with the requirements for age and connection with Scotland as set out in the Bill? No.

**Question 3:** Are you satisfied with the two categories of people who would qualify to be assisted under the terms of the Bill? No.

**Question 4:** 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? No.

**Question 5:** Do you consider the level and nature of safeguards as set out in the Bill to be appropriate? No.

**Question 6:** Do you have any other considerations on the Bill not included in answers to the above questions?

Further concerns and discussions relating to euthanasia and assisted suicide can be found at: www.schb.org.uk (publications).

Dr Calum MacKellar
Director of Research
Scottish Council on Human Bioethics
11 May 2010
End of Life Assistance (Scotland) Bill

Mark Hazelwood, Director

Scottish Partnership for Palliative Care

About the Scottish Partnership for Palliative Care (SPPC)

The Scottish Partnership for Palliative Care (SPPC) is the umbrella body representing the major organisations involved in palliative care in Scotland. Our membership includes all 14 territorial health boards, all 15 of Scotland’s voluntary hospices, 18 major national health charities, 7 professional associations and 1 local support organisation. The membership of the Partnership is detailed at www.palliativecarescotland.org.uk. Through a collaborative approach, the Partnership supports and contributes at national level to the development and strategic direction of palliative care in Scotland and the promotion of service improvement at local level. The Partnership’s aims are to promote equitable access throughout Scotland to high quality palliative care for all patients and families on the basis of need not diagnosis.

SPPC Position Statement on Legalisation in Principle

The SPPC is not able to adopt a position on the principle of whether or not physician assisted suicide and voluntary euthanasia should be legalised. This is because the topic raises issues of a moral, personal and ethical nature upon which many of our member organisations (for example our member health boards) are institutionally unable to hold a position.

However, the SPPC holds the view that in attempting to legislate in this area MSPs should give careful regard to:-

Any possible damage to the practice and provision of palliative care. Palliative care benefits thousands of people in Scotland each year.

The protection of vulnerable people. All people are potentially vulnerable, depending on events and circumstance.

The content of this submission is guided by these twin considerations. The submission aims to support the deliberation of MSPs both by providing relevant factual information and also by directing the attention of MSPs to questions of practical relevance to these twin considerations. MSPs are also encouraged to examine the report and recommendations of the House of Lords Select Committee on the Assisted Dying for the Terminally Ill Bill.

About Palliative Care

Palliative care is the term used to describe the care that is given when cure is not possible. The word comes from the Latin ‘palliatius’ (covered or hidden with a cloak) and is used to mean ‘relieving without curing’.

Palliative and end of life care are integral aspects of the care delivered by any health or social care professional to those living with and dying from any advanced, progressive or incurable condition. Palliative care is not just about
care in the last months, days and hours of a person’s life, but about ensuring quality of life for both patients and families at every stage of the disease process from diagnosis onwards. A palliative care approach should be used as appropriate alongside active disease management from an early stage in the disease process. Palliative care focuses on the person, not the disease, and applies a holistic approach to meeting the physical, practical, functional, social, emotional and spiritual needs of patients and carers facing progressive illness and bereavement. The World Health Organisation (WHO) defines palliative care thus:

“Palliative care is an approach that improves the quality of life of patients and their families facing the problems 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. Palliative care:

provides relief from pain and other distressing symptoms;
affirms life and regards dying as a normal process;
intends neither to hasten or postpone death;
integrates the psychological and spiritual aspects of patient care;
offers a support system to help patients live as actively as possible until death;
offers a support system to help the family cope during the patient’s illness and in their own bereavement;
uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated;
will enhance quality of life, and may also positively influence the course of illness;
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.”

Specialist palliative care focuses on people with complex palliative care needs (e.g. complex pain management or psychological support) and is provided by a team of professionals who specialise in palliative care (e.g. consultants in palliative medicine and clinical nurse specialists in palliative care). General palliative care forms part of the routine care of patients and support for carers. It may be part of the work of a range of health and social care practitioners including GPs, care assistants and hospital staff.

There is a common misconception that the use of opioid medicines to control pain in palliative care shortens life in dying patients. In appropriate doses the opioid medicines (e.g. morphine) do not shorten life. There is no robust evidence to support the assertion that medical staff use opioid medicines to shorten deliberately the life of patients.
The views, feelings and wishes of patients change over time and may alter frequently during the course of an illness. Patients who wish to get assistance to die because of distressing physical symptoms often change their minds when these symptoms are addressed through appropriate palliative care.

Living and Dying Well (2008) is the Scottish Government’s ambitious action plan for palliative and end of life care. The plan describes how palliative care will increasingly be available to patients and families regardless of their diagnosis, prognosis or place of care. Work is progressing across Scotland to improve the identification and assessment of people with palliative care needs, and to better meet those needs identified. Audit Scotland’s Review of Palliative Care Services in Scotland (2008) suggests that over 40,000 people in Scotland each year could benefit from palliative care.

ISSUES FOR PARTICULAR CONSIDERATION BY MSPs

(numbers quoted refer to sections and sub-sections of the Bill)

Terminology and the Practice of Palliative Care (1 & 2)

MSPs are asked to consider whether the Bill’s use of the term “end of life assistance” with the associated definition (1.2) could create serious difficulties for the practice of palliative care. As drafted the definition of “end of life assistance” would cover euthanasia and assisted suicide. The definition would also include existing routine practice in palliative care.

As the Bill is currently drafted it is unclear whether the practitioners providing palliative care (for example pain killers, or psychosocial support – both assistance at the end of life) could only do so under the terms of (2) i.e. following two formal requests.

MSPs are also asked to consider whether this terminology in the Bill could also hamper communications between patients, healthcare staff and families. It is fundamental in palliative care that practitioners explore the needs and wishes of patients as the end of life approaches, aiming to assist them to die with dignity and a minimum of distress. Practitioners may also seek to surface in discussion a patient’s feelings of hopelessness in order to be able to explore the causes of those feelings and hence plan care to meet the patient’s needs. This process may involve exploring with the patient whether they are having suicidal thoughts. It would be easy, given the imprecise terminology used by the Bill, for patients involved in such exploration to believe that a practitioner was suggesting euthanasia or suicide when this was not the case (and for them to reach the potentially devastating conclusion that their doctor did not believe their life was worth continuing). These terminological imprecisions could also impact on discussions between patients and their families and friends. The complex, sensitive and nuanced communications which are at the heart of caring for people towards the end of their life risk being compromised when terms such as “assistance”, “distress” and “dignity” become clouded with double meaning. There is potential for informed decision-making by patients to be made more difficult.
Alternative and more clearly defined and understood terms such “euthanasia” and “assisted suicide” are available.

MSPs are asked to consider whether assisted suicide and euthanasia are equivalent in all regards and if not whether a single legislative framework which does not distinguish between them is likely to represent an optimal arrangement.

MSPs are invited to consider whether systems and processes to provide assisted suicide/voluntary euthanasia in which the medical profession are less centrally involved might reduce potential damage to the practice and provision of palliative care.

**Eligibility Requirements**

MSPs are asked to consider whether in (4.2.a) the criterion “incapacitated to such an extent as not to be able to live independently” is imprecisely worded such that it is capable of multiple and widely varying interpretations. MSPs are invited to consider whether this leaves the scope of the proposed legislation unclear. Lack of sufficient clarity could leave both doctors and persons seeking voluntary euthanasia/assisted suicide in unsatisfactory positions.

(4.4) For many medical conditions, particularly non-malignant conditions, it is difficult to predict whether death is likely to occur within six months.

**Consent and Verification Process**

Duty on designated practitioner and psychiatrist to discuss hospice care and palliative care (7.1.a, 9.2.b)

MSPs are asked to consider whether the Bill is sufficiently clear as to what this discussion should entail:- are the designated practitioner and the psychiatrist assessing the palliative care needs of the individual or describing such services and their potential benefits? Either way, MSPs are invited to consider whether the Bill should make provision that the designated practitioner and psychiatrist be sufficiently qualified, knowledgeable and experienced to undertake the envisaged discussions.

**Issues Related to the Assessments (7 & 9)**

The multiple assessments contained in the Bill are to be welcomed. However, designated practitioners and psychiatrists will potentially face challenges. Severe mental disorder or blatant coercion may be readily detectable, but a potentially common combination of factors affecting a requesting person (mild depression, mild cognitive impairment and an internalised perception that they are a burden to relatives) may be much more difficult to identify. MSPs are encouraged to consider how safeguards in respect of this and other groups could be strengthened.

The Bill does not require the assessing designated practitioner to have any prior knowledge of the requesting person or their social and family
circumstance. The psychiatrists conducting the assessments may meet the requesting person only once.

It is not clear why the psychiatrist but not the designated practitioner is required to discuss “the requesting person’s reasons for, and feelings with regard to, the decision to seek end of life assistance” (9.2.e). It would seem that any designated practitioner assessing a request should be required to explore these issues directly with the requesting person.

Cooling Off Periods and Deadlines

MSPs are asked to consider whether the cooling off periods, deadlines and revocation arrangements contained in the Bill could create an undesirable dynamic in which a vulnerable person feels impelled to proceed. Having spent their own time and money (and the time of multiple witnesses and practitioners) in respect of four assessments the requesting person will have a relatively short period in which to act (or face having to go through the whole process again). The willingness of patients to discuss with practitioners any doubts about proceeding with the process may be inhibited by (3.1) which says that any notice “however informal” that the patient doesn’t wish to proceed will revoke the initial request. In Oregon, where there are no such deadlines, many patients who are granted suicide assistance (through the prescription of medication) choose ultimately not to take the medication, though they retain access to it.

Agreement on Provision of Assistance (10)

The Bill does not require that the written agreement on the details of the provision of voluntary euthanasia/assisted suicide is based on a meeting or discussion between the requesting person and the designated practitioner.

MSPs are asked to consider whether it would be prudent for the Bill to stipulate that the agreement should state what action the registered practitioner (or others) are to take in the event of medical complications (e.g. failure to die, unexpected side effects). Other non-medical complications should also be considered (e.g. the non-availability at short notice of the designated practitioner due to sickness).

Requirements Relating to the Actual Provision of Assistance (11)

MSPs should consider how the risk of complications and untoward events could be minimised during the actual provision of voluntary euthanasia/assisted suicide given that: the Bill places no restrictions on the range of methods which may be used to carry out the voluntary euthanasia/assisted suicide. The Bill makes no requirement about the competence of the individual providing voluntary euthanasia/assisted suicide. Medical personnel do not have training or experience in voluntary euthanasia/assisted suicide. The Bill would sanction members of the public to undertake medical procedures for which they have had no training and would appear to sanction members of the public to undertake any act which would result in the death of
the patient, so long as that act is contained in the agreement between the designated practitioner and the requesting person.

**Clarity Regarding the Roles and Responsibilities of Practitioners**

MSPs are asked to consider whether the Bill provides sufficient clarity about roles in order to protect practitioners involved. The Bill outlines the role and responsibility of the “designated practitioner” and the assessing psychiatrist only. However, both specialist and general palliative care (in fact most health and social care) are provided by teams and so the Bill may impact on/invoke a much wider group of professionals which could include nurses, pharmacists, healthcare assistants, social workers, care workers, psychologists etc. all of whom might be expected to have contact with the patient requesting euthanasia or assisted suicide. What are the roles and responsibilities of the members of this team? For example, if the requesting person says to his Macmillan nurse that he is “no longer so sure about receiving assistance” does this count as giving notice of revocation (3.1)? Should the designated practitioner have a legal duty to inform other members of the care team at the outset that a patient has made a request for euthanasia/assisted suicide so that they can be alert for revocation or to signs of undue influence, incapacity or mental disorder? How will issues of conscientious objection be handled in this team setting? The Bill is silent on all issues concerning conscientious objection.

MSPs are asked to consider whether the Bill should specify the standards of diligence expected in regard to the roles of practitioners, in order to provide clarity and reassurance to practitioners in the event of post mortem allegations, investigations by the Procurator Fiscal’s Office and possible prosecution. For example, in satisfying themselves that a patient is not acting under any undue influence should the designated practitioner proactively investigate relevant family dynamics and social background? Should criminal record checks be required? Should the financial circumstances of patients and families (including provisions in Wills) be identified? If a designated practitioner does not feel qualified to make these financial/forensic assessments should the Bill impose a duty on him/her to take further expert advice?

**Recording, Reporting and Monitoring Arrangements**

The Bill does not describe arrangements for reporting on and monitoring the provision of voluntary euthanasia/assisted suicide, although it is understood that the Procurator Fiscal’s Office would have the power to investigate. A more robust reporting regime, based on appropriately formal documentation of the whole process, which generates a clear data set, could allow for monitoring, scrutiny, audit, regulation and research into a highly controversial, contested and potentially evolving area of public policy. MSPs are invited to consider this.

**Conflicts of Interest**
MSPs are asked to consider whether in the event of a registered practitioner specialising in the provision of voluntary euthanasia/assisted suicide through private practice it may become difficult to interpret (5.2.b). Such a practitioner may be charging “reasonable fees”, but since his or her income could be wholly or largely dependent on providing voluntary euthanasia/assisted suicide there could be a perceived conflict of interest.

**Oral Evidence**

As the umbrella organisation representing the major organisations involved in palliative care in Scotland the SPPC would welcome an opportunity to participate in future oral evidence sessions of the Committee.

**Background to Internal Consultation on this Evidence**

The membership of the SPPC was consulted on the content of this submission. 30% of nominated member representatives responded to the consultation. Of these responses 93% supported the submission.

References to support the evidential assertions in this submission are available on request to the SPPC.

Mark Hazelwood, Director

Scottish Partnership for Palliative Care

10 May 2010
End of Life Assistance (Scotland) Bill

Independent Association of Nurses in Palliative Care

The Independent Association of Nurses in Palliative Care (IANPC) was recently created by a group of experienced palliative care nurses to ensure that good quality palliative care is available to those who require it regardless of diagnosis or place of care. The aims of IANPC are:

To promote palliative nursing education through the provision of educational events

- To inform international, national and local palliative care strategies, policies and systems of care
- To share good palliative nursing practice through a dedicated website and an electronic newsletter
- To oppose the legalisation of euthanasia/assisted suicide in the UK

Using the questions suggested in the response guidance information as section headings this document answers the specific questions, asks for further clarification on some issues and clarifies why IANPC takes this stance against assisted suicide.

1. Do you agree a person should be able to request end of life assistance from a registered medical practitioner?

No.

IANPC firmly believes that such legislation puts medical practitioners in a position that few would choose to be in. Indeed many Doctors may have sound ethical and moral reasons not to be involved in what in effect is life ending treatment. This may lead to only a few medical professionals and their associated teams dealing with many of the cases that come forward. Would Scotland then be in danger of creating its own Doctor shopping system like Oregon?

We also believe that such legislation would have a negative impact on the therapeutic relationship developed between all practitioners (not just doctors) and dying patients which could result in dying people being unable to discuss their innermost issues in the fear that this may lead to them being assisted to die. We already know that there is evidence of “involuntary” euthanasia being practiced in countries where this type of legislation is already in place and believe this abuse would happen in Scotland too.

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

No.
IANPC suggests that young people above 16 but still in adolescence, although legally defined as an adult, may not have the necessary life experience or maturity to make such a decision. Many of these young people will have been ill for many years and are coping with the change to adulthood as well as the issues their illness presents to them. It is therefore not fair or appropriate to allow them to consider ending “an intolerable situation” during this often turbulent time in a young person’s life. Indeed cases have been presented as part of earlier attempts to legalise assisted dying in the UK to show that an “intolerable” situation in adolescence can become one that is very tolerable in adulthood.

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

No.

Indeed IANPC would suggest that the two categories identified in the Bill can be interpreted in so many different ways that a significant amount of Scots could avail themselves of assisted suicide were it to become law. We identify our concerns more fully below.

♦ The term terminally ill is often used for people whose life expectancy is defined in weeks and months rather than years and in the Bill suggests these people would have a life expectancy of less than 6 months. However there is clear evidence to suggest that it is very difficult to say with any authority how long people with an advanced life limiting illness have left to live. A much clearly definition is required to prevent abuse of assisted suicide legislation.

♦ There are immense problems regarding the use of the adjective “intolerable”. IANPC suggests that the word is highly subjective, and by its very nature could make assisted dying available to many more people than was initially intended. Indeed currently many patients coming into specialist palliative care services for care and support report that they are suffering from intolerable symptoms and issues. However following a period of intense management using the expertise of a specialist team the majority then experience satisfactory levels of quality of life and enjoy the remaining time they have left with their families. It would therefore seem that a more proactive approach in allowing people who are suffering intolerably to access this type of care rather than pushing through any new assisted suicide legislation should be employed.

♦ We are also concerned about the people who are classed as those who are permanently physically incapacitated and unable to live independently. Again this could have a very wide interpretation. It could include people with sensory impairments whose life is not limited by their affliction. It could also apply to anyone else who has a disability/illness that prevents them from living independently. IANPC firmly believe that this would open the door to a system that allows the assisted death of just about anyone who can prove that they cannot live independently and that this causes them to suffer.
4. **The Bill outlines a two-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?**

No.

As we have noted above IANPC believes that only a few Doctors or Psychiatrists would wish to be part of this process and as such we believe that this increases the chance of the process being managed less rigorously. This could then lead to requests for assisted dying to be rubber stamped with little regard for objectivity in assessment process. This may be especially true if a payment for the assisted dying service is being paid to such practitioners.

We also note that the designated practitioner need not be the Doctor the person requesting assisted suicide is registered. In these circumstances how can the designated practitioner fully assure themselves that the applicant meets the criteria for an assisted death?

IANPC believes that a discussion of alternatives such as palliative care is not sufficient. There is a vast difference in hearing about a means of care than actually experiencing it. We would suggest that applicants need to agree to having trial of palliative care provided by specialist practitioners as is the case in Belgium. Here the experience of palliative care often leads to a withdrawal of the application. We also feel that the cooling off period is too short and would not allow for the exploration of other means to reduce the person’s suffering such as a trial of palliative care.

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

No.

One of the safeguards in the Bill is that the person requesting assistance to die should have been registered with a medical practice for at least 18 months prior to the request. What safeguards are there to prevent people living elsewhere registering with a Doctor who practices assisted suicide but not actually using their service. There are many ways around the system of registering with a medical practice to make use of the assisted suicide law. Does Scotland really want to be recognised as a “death tourism” destination?

The Bill does not really give the reader any information on the means that would be used to assist in a person’s death. This means that those requesting assisted suicide are unable to make a fully competent decision about what is in their best interests as they do not know how this act will be carried out. E.g. is it painful, involve injections and so on.

IANPC notes that there is no conscience clause in this Bill to safeguard health and social care practitioners who do not wish to be involved in assisted suicide. We feel that many practitioners’ belief systems would not allow them to be party to this and that this could affect their choices in employment.
6. Do you have any other considerations on the Bill not included in answers to the above questions?

Yes.

The Explanatory Notes suggest that if the “Oregon” Model is followed in Scotland, potentially 55 people per year would end their life through the use of the Act, which may result from this Bill. However this Bill would seem to include euthanasia as it states that the means includes “the administration of appropriate means” and talks about “persons who wish their lives to be ended”. This would significantly increase the number of such requests and we would ask if the safeguards identified in the Bill would have the capacity to cope with this?

In addition IANPC is concerned that the Bill makes no mention of the role of any professionals other than Doctors, although it suggests someone other than the designated medical practitioner could provide the assistance to die. In other countries where euthanasia is available there is a significant role for nurses as they are in more contact with dying people than any other professional group. Further clarification is required about who and who cannot be part of this process.

The Explanatory notes suggest that the Crown Office Procurator Fiscal Service would have the power to investigate any deaths which give rise to public concern. What safeguards will NHS Scotland and other healthcare providers have in place to monitor and investigate the use of the assisted dying service?

As with any changes in medical treatment or healthcare there is the potential that the promotion of assisted suicide might be fuelled by an economic agenda. Assisted suicide has the potential to save NHS Scotland and Local Authority Social Care Services a substantial amount of money that would otherwise be used to provide continuing care and palliative care to this vulnerable group of people. What safeguards are in place to ensure that this does not occur?

Finally we note that the designated practitioner is obliged to be present at the applicant’s death. We are not sure why this is especially if the applicant self-administers the medication. This needs to be clarified more fully as it suggests that the designated practitioner is administering the assistance to die.

Elaine M Stevens
Chair
The Independent Association of Nurses in Palliative Care
7 May 2010
End of Life Assistance (Scotland) Bill

ACT

About ACT

ACT is the only organisation working across the UK to achieve the best possible quality of life and care for every life-limited or life-threatened child or young person and their family. ACT supports a children’s palliative care professional and family membership across the UK and provides a national helpline and information service.

ACT produces a range of publications and resources, including care pathways for life-limited or life-threatened children and young people, and publishes the International Journal for Children’s Palliative Care.

ACT takes a lead on lobbying and campaigning for sustainable children’s palliative care services and plays a key role in ensuring that the needs of all affected children and their families are heard.

This response was developed by ACT’s Ethics Committee. In addition, ACT’s 1000 members were consulted via the charity’s website and respondents were in agreement with the responses contained within this document.

ACT considers that the questions which are relevant to our sphere of interest (children and young people’s palliative care) relate to age and capacity and require a response from us and these are:

1. Are you satisfied with the requirements for age and connection with Scotland as set out in the Bill?
2. Are you satisfied with the two categories of people who would qualify to be assisted under the terms of the Bill?
3. Do you consider the level and nature of safeguards as set out in the Bill to be appropriate?

Response

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

No - ACT believes that age is not the only determinant of the capacity of a young person to make decisions.

ACT recognises that the age of 16 reflects the age of majority and that in general law functions, age determined definitions are used but believes that an age related decree in relation to decision making does not take into account the capacity of the young person to make decisions.
The inclusion of young people from the age of 16 and the psychiatric assessment should ensure that developmentally appropriate considerations are included. It is imperative that any assessments do not merely exclude significant psychopathology, but also is carried out by practitioners who have the expertise to assess full capacity and who are able to recognise the impact of the speed of emotional development in late adolescence and the rapid swings in emotion on decision making. Currently young people in Scotland would be assessed by adolescent mental health services, who will have the skills to assess age-related issues, but may not have the knowledge to assess capacity in relation to the decisions relating to assisted suicide.

Assessment of mental capacity is increasingly moving away from an age-based ability to make assessments towards a capacity to make decisions. There is a need to balance age-specific and decision specific issues and for consideration to be given to ensuring that the level of the competency test is set higher for complex and very serious tasks.

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

No - defining the categories in the way suggested by the proposed Bill is not possible in practice.

The inclusion of a terminal illness as a qualifying condition requires clinicians to be able to provide an accurate prognosis in an uncertain speciality. This is especially problematic in the case of young people with non-malignant conditions.

The concept of physical incapacity and the related lack of ability to live independently do not reflect the complex dependence-independence relationship which is a normal facet of growing up and maturing. The degree of incapacity related to a reliance on others does not necessarily purely reflect a physical dependence, but includes varying degrees of emotional, psychosocial and even financial dependency.

Intolerability is a subjective measure and is therefore variable for individuals and is unsuitable as a criterion for determining best interests. Many individuals have borderline capacity, which will lead to such decisions/judgements being made by others on their behalf. If a person, and particularly a child, does not have capacity then someone else (and ultimately the court) has to determine best interests. In English law, following Mr Justice Wall's comments in the Charlotte Wyatt case, a determination of intolerability by proxy now plays a much less important role in the determination of best interests than it used to. The question is "intolerable to whom?" It is almost impossible not to make some kind of substituted judgement when the patient cannot express what is intolerable to him or herself. When considering
assisted dying, having two doctors making two assessments will be no safeguard if the criteria applied to those with reduced capacity are inappropriate. The later GMC v Burke judgement also discarded it as a legal concept for adults, although ACT recognises that ‘unbearable’ is still an ethical concept.

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

No. The proposed measures do not adequately protect children under the age of 18yrs. The safeguards are unlikely to protect the vulnerable who seek to end their life because they feel a burden to others, or who cannot see a reasonable alternative. There is little recognition of the need for independent advocates to protect the vulnerable individual.

Other points

ACT welcomes the national strategy for palliative and end of life care (Living and Dying Well, Oct 2008) and believes that the Government should actively promote excellence in palliative care and adequately fund palliative and end of life care.

ACT believes that all babies, children and young people should have access to choice in their place of care and their place of death and that they should be provided with the support necessary to achieve a “good” life and a “good” death. A good death not only benefits the ill child or young person, but also their loved ones and carers.

ACT considers the title of the Bill ‘End of Life Assistance’ to be inappropriate as there is a lack of clarity in what End of Life Assistance means. The process reflected within the documentation would be more accurately described as euthanasia and assisted suicide and the implications of both processes should be described within the Bill.

The Bill fails to recognise the involvement of other professionals in the proposed process – and merely focuses on the role of doctors, and not on the

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1 “As a society, we fight shy of pondering on death, yet inherent in each of us is a deep desire, both for oneself and for those we love, for a ‘good’ death. It would be absurd to try to describe that concept more fully beyond saying that everyone in this case knows what it means: not under anaesthetic, not in the course of painful and futile treatment, but peacefully in the arms of those who love [her] most.” – Mr Justice Hedley, High Court Ruling on the Charlotte Wyatt case, 7 October 2004
roles of nurses, carers and pharmacists who could all be involved in the role of assistant. There is no provision for practitioners who would choose to opt out of this process and the Bill does not provide adequate legal protection for practitioners who choose to engage around the final act of assistance.

ACT is concerned that these proposals will bring about differences in treatment for those aged 16-18 between England and Scotland.

Ms Lizzie Chambers
Chief Executive
ACT
11 May 2010
End of Life Assistance (Scotland) Bill

Highland Hospice Inverness

Highland Hospice provides specialist palliative care and advice for patients throughout Highland, with advanced, incurable disease and a short life expectancy, regardless of diagnosis. We endorse the WHO definition and principles of palliative care. Our position on euthanasia and assisted suicide has been established in wide consultation with our staff, volunteers, and community supporters, and is endorsed unanimously by our Board of Directors.

For the sake of brevity in this submission we will use the term ‘assisted dying’ to mean either euthanasia or assisted suicide. Similarly reference to ‘the Bill’ will mean the Bill itself and the accompanying Explanatory Notes and Policy Memorandum. We recognise that these accompanying documents have no standing in law, but they are in the public domain and will be influential. It is therefore valid to comment on them.

In addition to this written submission, we would welcome the opportunity to contribute to the oral evidence being gathered by the Committee.

Do you agree a person should be able to request end of life assistance from a registered medical practitioner?

We stand resolutely against assisted dying which, contrary to the assertions of the Bill, is at variance with the principles and practice of palliative care. One of the many defining characteristics of palliative care is that death will never be intentionally hastened. Much of our inspiration comes from Dame Cicely Saunders – the founder of modern hospice care - who said that in palliative care, “We do all we can not only to help you die peacefully, but also to live until you die”. We must do everything possible to maximise the value and potential of life, rather than deliberately ending life. A change in the law to permit assisted dying would create a paradigm shift in the principles of health and social care in our society, away from that fundamental requirement to respect and promote life, embodied in Article 2 of the Human Rights Act 1998. This Bill challenges that fundamental requirement for people with terminal illness or physical disability. Legalised assisted dying would create ethical and legal dilemmas for health care professionals, who have come under increasing scrutiny over recent years in order to assure safe practice. We recognise the strong public opinion in favour of such legislation. However we contend, with good evidence, that public opinion is obscured by lack of information and opportunity for informed reflection on the implications of a change in the law, and as such, does not provide a safe basis for legislative change, particularly when human life itself is at stake.

This Bill declares its purpose to be the legalisation of the means necessary to enable a person to die with dignity and a minimum of distress. That provision is already made in health care. Palliative care in particular is directed to precisely these objectives. There is no indication whatsoever, in any of the documentation, why the provisions of this Bill meet the purported need.
Are you satisfied with the two categories of people who would qualify to be assisted under the terms of the Bill?

Eligibility criteria include terminal illness with an anticipated prognosis of six months or less, or physical incapacity which renders a person dependent on others, plus the finding of life to be intolerable. The six month prognosis is a common figure in proposals for assisted dying, but is an arbitrary figure. Determination of prognosis is notoriously inaccurate in malignant disease and even moreso in terminal non-malignant disease. It would also be difficult for a doctor to determine whether or not the degree of dependence was sufficient for the purposes of this Bill, all the more difficult because each of us is inevitably dependent on others in most aspects of life, even in health. The Bill acknowledges that intolerability is subjective, but gives no indication as to how this should be evaluated. Recent evidence indicates that unbearable suffering is transitory amongst those who request assisted dying\(^4\) and it cannot be relied upon as a firm basis on which to make a decision to end life.

We have major concerns about the imposition of assisted dying in the palliative care environment. In our experience, determined requests for assisted dying are exceptionally rare. Our work includes sensitive exploration of and support for the psychological or spiritual distress which commonly accompany terminal illness. Our patients are able to disclose these issues in the safe knowledge that our only response will be to optimise the quality or quantity of remaining life. The legalisation of assisted dying would compromise that essential trust within the relationship between patients and clinical professionals. It would become impossible to engage freely with patients as we currently do, without the potential for accelerated death being on the agenda. Published experience supports the contention that assisted dying and palliative care are not compatible.\(^5\)

Expert palliative care is usually, but not always successful in ameliorating or alleviating suffering in advanced disease. Continued research and investment in health care is the right approach for those who cannot be adequately helped by current provision. The Bill acknowledges that legal access to assisted dying for some would create the potential for others to come under inappropriate influence or even coercion to consider this action. A right for the minority who determinedly wish assisted dying would threaten the care, safety and security of the majority.

Human dignity is a complex issue, not defined simply in terms of autonomy, dependency or capacity. We refute the implication that a dignified death can only be achieved by assisted dying. Our whole basis of care is dignity, achieved by detailed understanding and implementation of its components in health care.\(^6\)

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

We consider the safeguards to be unfit for purpose. There is no information about the format or management of any of the proposed documentation, or how
it itself should be scrutinised. The requirement for ‘discussion of feasible alternatives’ to assisted dying is difficult to interpret. What would comprise such discussion and what would be its purpose? Doctors develop expertise in particular areas of medicine, but may at the same time become less familiar with other areas. It cannot be safely assumed that the designated practitioner, whoever that may be, will have sufficient knowledge or expertise to competently discuss feasible alternatives, including palliative care.

The Bill requires two psychiatric assessments, but permits both to be conducted by the same person, who is only required to report that the patient is acting voluntarily and with capacity, and not on how appropriate it is to continue with the process. The final decision as to whether the process should be carried through rests solely with the designated practitioner. In a matter of such consequence, second opinion should indeed be mandatory, but should also be independent and above reproach. Approval of the second request by the same doctor who approves the first can hardly be construed as an independent second opinion! There is no indication of criteria by which the doctor or the independent witnesses should establish that the requesting person is acting voluntarily and without undue influence, what rigour would be required for this, or how any disagreement would be adjudicated. The provision for revocation of the process at any stage, ‘however informally’, creates a dilemma for the doctor dealing with any expressions of distress by the requesting person. How does a doctor qualitatively evaluate statements or questions in this context? Do indications of hesitation or doubt, or concerns about the family, so commonly expressed by people approaching death, constitute informal revocation? This supposed safeguard may actually inhibit the open and supportive dialogue with the doctor which is so important when approaching death. Moreover, there is no requirement in the Bill that any expression of hesitation to someone else should automatically be passed on to the doctor, rather than suppressed with well meaning or malicious intent.

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

This Bill disregards many of the recommendations of the House of Lords Select Committee specifically intended to guide the drafting of such legislation. It does not draw a clear distinction between assisted suicide and voluntary euthanasia, or set out clearly the actions which a doctor may and may not take in either case. There is no guidance whatsoever on what a doctor may or may not do, or agree to, in bringing about the person’s death. Discussion with one of our local Consultant Psychiatrists convinces us that the Bill does not adequately address the need to identify psychological or psychiatric disorders.

Whilst the wording regarding prognosis in terminal disease is an improvement on previous legislative attempts, the Bill does not acknowledge the everyday clinical realities of prognostic inaccuracy. It does not focus on unrelievable suffering, but only on intolerability. In making provision only for *discussion* of palliative care, the Bill does not encourage patients to *experience* such care.
before taking a final decision. Finally it makes no allowance for conscientious opt-out for doctors, and we find this particularly objectionable.

This Bill is substantially dependent on doctors. Whilst some UK doctors do favour euthanasia and assisted suicide, the majority are opposed.\(^7\) This Bill places onerous and inappropriate responsibilities on doctors, without prior focussed consultation with the medical profession. As the only professionals implicated in the process, it must be assumed that doctors will be responsible for ensuring that eligibility criteria are met by the requesting person, the witnesses to written requests, and any other person involved. Reliable verification of these criteria, with appropriate background searches, is a legal function for which doctors have neither the time nor expertise. The inevitable involvement of lawyers would escalate the cost to the requesting person which would offset, or more likely overtake any potential savings in the provision of ongoing health care.

The Bill states that actual means of terminating life will best be left to the expertise of doctors. Doctors work to save and preserve life and do not have expertise in its deliberate termination. Furthermore, the provision of health care is based on the establishment of competency. The Bill gives no indication of what competency in life-ending intervention will be required, or how that would be achieved. The same applies to lay personnel who, under the provisions of this Bill, may deliver the life-ending intervention. The Bill makes no comment about personal and professional support for participating personnel, and seems to suggest that training requirements would be nominal. The implication that assisted dying should be just another strand of health care is naive, and misguided about the gravity of any such decision or intervention.

Contrary to assertions that assisted dying is practiced in secret, recent published evidence indicates that doctors in the UK are rarely involved in such practices.\(^8,9\) The implication that this Bill would legalise something which is happening commonly and covertly, is not justified.

Several evocative anecdotes of suffering are cited. Numerous equally evocative anecdotes could be cited to support the opposite view. The debate on assisted dying will inevitably be passionate, on both sides, but in a matter of such gravity, also needs to be rational and objective, particularly since there is a need to address the acknowledged inadequacies of public opinion.

The Policy Memorandum quoting Dworkin says; “Death – the final act of life’s drama - should reflect our own convictions, not the convictions of others forced on us in our most vulnerable moment.” Although intended to support the Bill, this statement, bearing in mind the relative numbers involved, is a powerful argument against it.

In summary, this Bill does not establish that there is a need for assisted dying, nor does it explain why it provides for a better death than current palliative care services do. Essential detail is lacking, the safeguards are vacuous, crucial questions remain unanswered, and much is left to speculation. It is particularly vague about the ultimate action it seeks to authorise, and it fails to demonstrate an understanding of the principles and practice of medicine. We hope that the
Bill will progress to well-informed Parliamentary debate, and be exposed – and defeated - in that arena.

Maria McGill
Chief Executive
Highland Hospice
10 May 2010

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About St Andrew’s Hospice

St Andrew’s Hospice has been caring for the people of Lanarkshire since it was founded in 1986 by the Sisters of Charity. It provides specialist palliative care services and provides care of patients with progressive disease and limited prognosis including physical, emotional, psychological and spiritual care. The Hospice is open to all without distinction of race, gender or creed. It has grown in the past 25 years to support the needs of the community and it now offers:

- 30 bedded specialist palliative care unit
- 2 bed respite care service
- A day hospice offering care for up to sixty patients every week
- A care at home service, for those patients who chose to want to die at home.
- A specialist range of support services
- A consultant led domiciliary service
- Three symptom management clinics per week
- A telephone palliative care advice line
- An education service to support the understanding of palliative care in Lanarkshire.
- The involvement of the hospice medical staff in palliative care provision in the three District General Hospitals and clinics across the county.

St Andrew’s Hospice is recognised as a registered charity by the Office of the Scottish Charity Regulator (OSCR). (Charity no: SC010159).

In April 2006, the hospice became a company limited by guarantee with charitable status and changed its formal name to become St Andrew’s Hospice (Lanarkshire). In its day-to-day business, however, it retains the operational name of St Andrew’s Hospice.

Palliative care is an approach that improves the quality of life of patients and their families facing the problems 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. Palliative care:

- Provides relief from pain and other distressing symptoms;
- Affirms life and regards dying as a normal process;
- Intends neither to hasten or postpone death;
- Integrates the psychological and spiritual aspects of patient care;
- Offers a support system to help patients live as actively as possible until death;
• Offers a support system to help the family cope during the patient’s illness and in their own bereavement;
• Uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated;
• Will enhance quality of life, and may also positively influence the course of illness;
• 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.”

Specialist palliative care focuses on people with complex palliative care needs (e.g., complex pain management or psychological support) and is provided by a team of professionals who specialise in palliative care (e.g., consultants in palliative medicine and clinical nurse specialists in palliative care). General palliative care forms part of the routine care of patients and support for carers. It may be part of the work of a range of health and social care practitioners including GP’s, care assistants and hospital staff.

Management Team & Medical Staff Response to the End of Life Assistance (Scotland) Bill

We have concerns about the title of this Bill; The End of Life Assistance (Scotland) Bill. From the title at the start and throughout we feel that this Bill uses language in a misleading way. End of life assistance is provided by specialist and general palliative care practitioner teams by means of high quality symptom management (emotional, physical and spiritual). It is not intended to shorten life but to alleviate suffering. Therefore, we feel that the term “end of life assistance” has been hijacked by this Bill possibly to disguise its real aim, which is to legalise the intentional ending of life by either assisted suicide or euthanasia.

The Bill states that end of life assistance means including the provision or administration of appropriate means to enable a person to die with dignity and the minimum of distress. We feel that the word dignity has been used inappropriately. There is no attempt to define what is meant by dignity or a dignified death. However, there is a heavy suggestion that dignity is something, which people can clearly identify with and clearly define and that assisted dying will always be dignified. We would suggest that a dignified death is very difficult to define; it is very subjective. We feel that most people have a good and dignified death. We suggest that these emotive and subjective terms should not be used in this Bill.

Do you agree a person should be able to request end of life assistance from a registered medical practitioner?

This Bill requires two formal requests in order for assisted suicide/euthanasia to be provided and it is suggested that these requests be made to a registered medical practitioner and that these requests have to be approved by that
practitioner. As far as we can see, an assumption has been made that the medical establishment in Scotland would agree to engage with this process. As far as we are aware, the medical profession has not been consulted on this Bill and we feel that it is presumptuous for authors of the Bill to assume that doctors will become involved. The medical profession exists to treat, cure and care for sick and disabled people. There are many who feel that doctors should stay clear of assisted suicide or, more accurately, of putting people to death if they want to retain the trust of their patients. If doctors were given the option to end life, the doctor/patient relationship would never be the same again. It is a fundamental part of specialist palliative care that medical staff explores physical, emotional and spiritual symptoms at the end of life, with the aim of assisting patients to die with the minimum of distress. These discussions may be emotionally charged and it would be easy, given the ambiguous terminology used by this Bill, for patients to arrive at the conclusion that their doctor was suggesting euthanasia or assisted suicide when this was not the case. Therefore, we do not agree a person should be able to request end of life assistance from a registered medical practitioner.

Are you satisfied with the requirements for age and connection with Scotland as set out in the Bill? Are you satisfied with the two categories of people who would qualify to be assisted under the terms of the Bill?

Eligibility in this Bill includes anybody over sixteen years of age who has been diagnosed as terminally ill and finds life intolerable, or is permanently physically incapacitated to such an extent as not to be able to live independently and finds life intolerable. We are concerned that the word “intolerable” may be subject to wide interpretation. Also the phrase “incapacitated to such an extent as not to be able to live independently” is capable of widely varying interpretations. The above leaves the scope of the proposed legislation extremely unclear, for both professionals and persons seeking voluntary euthanasia/assisted suicide.

We ask MSPs to consider how this Bill, if introduced, will impact on Scotland’s National Suicide Prevention Strategy and Action Plan “Choose Life”, with its aim of reducing the suicide rate in Scotland by 20% by 2013 and which is supported by the government. In particular, MSPs are asked to take account of the age qualification of this Bill (sixteen years) and the real possibility that the Bill would allow assisted suicide for young, impressionable, vulnerable teenagers with ill-defined “capacity” and with subjective feelings of their lives being “intolerable”. What signal would this Bill send to the wider, young population of this country? Therefore, we are not satisfied with the requirements for age as set out in this Bill and we are extremely dissatisfied with the two categories of people who would qualify to be assisted under the terms of this Bill.
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?
Do you consider the level and nature of safeguards, as set out in the Bill, to be appropriate?

Section 6 (2) of the Bill states that witnesses must sign a statement that, to the best of the witnesses knowledge and belief: the requesting person understands the nature of the request, is making the request voluntarily and is not acting under any influence in making the request. We would be very concerned as to the reliability of these witness statements as numerous subtle pressures may be brought to bear on an individual who requests assisted suicide, which may escape anything but the most rigorous of scrutiny.

Section 7 (1) of the Bill states that before determining whether or not to approve the first formal request for end of life assistance, the designated practitioner must physically meet with the requesting person and discuss with that person; the medical condition referred to in section 4 (2); all feasible alternatives to end of life assistance, including hospice care and palliative care where relevant; the nature and consequences of the request including its revocability and the forms of end of life assistance which may be provided. We are concerned that the designated practitioner, who is likely to be a GP, may not have a suitable range of knowledge about palliative care and may therefore be ill equipped to provide appropriate advice to a patient who is seeking assisted suicide or euthanasia. This is also likely to be the case at the mandatory psychiatric interviews. Thus there is a real danger that all feasible alternatives may not be fully discussed.

In section 9 (1) and (2), it is apparent that the role of the psychiatrist is to consider the capacity of the applicant and not to provide a psychiatric report. This is of concern to us as a treatable depression occurs in over a third of patients with advanced progressive disease. However, the assessments required in this Bill do not include mandatory screening for depression.

There is no mention in the Bill about the level of seniority required by the designated practitioner and the psychiatrist who will be carrying out these assessments. It is of great concern that a junior, inexperienced member of the team may become involved. The fact that modern healthcare is practised in teams is completely overlooked in this Bill. The potential role of and impact on these professionals, including: nurses, pharmacists, social workers and chaplains are ignored.

The Bill is completely silent on the forms of end of life assistance, which may be provided. In addition to the ambiguous title of the Bill, such a stark lack of detail serves to further sanitise it. We would suggest that it is very difficult to comment adequately on safeguards without knowing the process in its entirety. However, we feel that the level and nature of safeguards, as set out in the Bill, are not appropriate and we have grave concerns about the consent and verification process.
Summary: (Other considerations on the Bill not included above)

The Management Team and medical staff at St Andrew’s Hospice believe that moves to legalise assisted suicide and euthanasia, such as this Bill, stem from fear in a small section of the population, of possible future adverse health related events and the concern that appropriate care and support may not be readily available. We believe that these fears should continue to be addressed by ensuring that palliative care and support, both specialist and non-specialist, is made available for all in Scotland. It is our experience that patients in a caring environment, who have their concerns adequately addressed, do not ask for euthanasia or assisted suicide. It is worth repeating that depression, often the root cause of patients feeling that their lives are no longer worth living, is treatable.

We feel that this is a poorly drafted Bill, which makes use of many emotive terms; it is extremely light on controls and assumes the support and involvement of medical staff. The Bill uses ambiguous terminology and hijacks words, which are used by organisations that do not support deliberate killing. This Bill appears to have been created for the few at the expense of the many: The many frail, vulnerable patients that we care for across a broad spectrum of age who are in danger of viewing the medical profession with fear and suspicion should this Bill be introduced. If this law reaches the statute book, there is a very real danger of it causing collateral damage well beyond the intended target area. The Bill does not explore the impact of euthanasia/assisted suicide on individuals, families, carers, clinical staff and society as a whole. The Bill implies that those who do not support it are showing no mercy and support for its introduction comes from a few opinion polls. However, the reality of working with people at the end of their lives shows that the experience of living with end of life issues is very different from abstract discussion when death and dying is distant. In other words, opinion polls have little or no bearing on the reality. Public opinion favours such legislation, but how well informed are the public about the ethical, medical and legal complexities and the practical implications, including the effect on families? This Bill makes assumptions about a doctor’s role in the deliberate ending of life but it is silent on conscientious objectors. St Andrew’s Hospice has had extensive experience of patients who have found life, at certain stages of their illness, intolerable. With multidisciplinary input and support, we have seen that quality of life improve, sometimes dramatically. The Management Team and medical staff at St Andrew’s Hospice believe that life is precious and oppose the End of Life Assistance (Scotland) Bill.

Postscript

A private members Bill that would have legalised euthanasia and assisted suicide in Canada, was strongly defeated by a vote of 228 to 59 recently. It was recognised that many people raised legitimate concerns and the goals now are to work with Canadian leaders to identify ways to:

- Improve palliative and hospice care throughout Canada
- To change attitudes and improve services for people with disabilities
Agenda Item 1
14 September 2010

- To institute an effective national suicide prevention strategy in Canada
- To promote programmes that identify and eliminate the scourge of elder abuse

Dr C J Sugden
Medical Director
Saint Andrew’s Hospice
10 May 2010