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Date: 28 February 2009 – Roseanna Cunningham MSP

Proposed Palliative Care (Scotland) Bill

Consultation response on behalf of the Scottish Council on Human Bioethics:

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 Scottish Council on Human Bioethics subscribe are set out in the **United Nations Universal Declaration of Human Rights** which was adopted and proclaimed by the UN General Assembly resolution 217A (III) on the 10th of December 1948.

The SCHB is very grateful to Roseanna Cunningham MSP for this opportunity to respond to the consultation on the **Proposed Palliative Care (Scotland) Bill**. It welcomes Ms. Cunningham's intention to promote public consultation, understanding and discussion on this topic.

Not all questions will be responded to.

Scottish Council on Human Bioethics Responses will be Presented after each Question:

Defining palliative care

There are various definitions of palliative care, but the following World Health Organisation (WHO) definition is internationally recognised and is proposed for the purposes of the Bill:

"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..."

The WHO outlines nine elements of palliative care. It:

- provides relief from pain and other distressing symptoms;
- affirms life and regards dying as a normal process;
- intends neither to hasten nor postpone death;
- integrates the psychological and spiritual aspects of patients' 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 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 radiotherapy and includes those investigations needed to better understand and manage distressing clinical complications.

Q1 What are your views on using this definition of palliative care for Scotland in the proposed bill?

Scottish Council on Human Bioethics Response

The SCHB is of the opinion that palliative care should address physical, psychological, social and spiritual aspects. In other words, it agrees with the definition from the World Health Organisation for Palliative Care.

However, the definition of palliative care by WHO whilst broad does not specifically address the fundamental problem of spiritual confusion experienced by patients with terminal illness. Whilst this can be neatly slotted under the rubric of 'psychological, mental and spiritual distress' it is ultimately too general a heading.

What may be needed is a greater analysis, research and even funding into how non-rational faculties play a core role in their connection with rational faculties i.e making sense of why a patient feels internally displaced, confused and distressed apart from his or her surrounding environment. Comfort through family and ease through care are external factors. But the internal factor of the soul is rarely discussed with patients. The idea of where existential confusions stem from and how they are linked to the brain in the discipline of neurology need to be given detailed attention to address the complexity of patients' concerns towards the end of their lives.

Finally, if the provision of palliative care is made a legal obligation, questions remain with respect to how tightly one would need to define palliative care to be able to measure whether it had been offered and whether all appropriate patients had received it. Logistically, it may not be possible to make this clearly measurable and it would have time implications for staff.

Who benefits?

Whilst palliative care is most often associated in the public mind with terminal cancer care, it is also of great benefit to patients with other progressive, life-limiting conditions. They include:

- Cystic Fibrosis
- Dementia
- Heart failure
- HIV/AIDS
- Motor Neurone Disease
- Multiple Sclerosis
- Muscular Dystrophy
- Parkinson's Disease
- Renal Failure and
- Respiratory Failure

Q2 What are your views on whether all progressive, life-limiting conditions should lead to an entitlement to palliative care?

Scottish Council on Human Bioethics Response

The SCHB is of the opinion that all progressive, life-limiting conditions should lead to an entitlement to palliative care in Scotland.

There is no need to withdraw or withhold nutrition and hydration unless clinically indicated in terms of its provision being impossible, futile or significantly disruptive to the dying patient's comfort.

Who provides palliative care?

Specialist palliative care is provided by multi-disciplinary teams whose members have trained specifically in palliative care. These include for example, consultants in palliative medicine, clinical nurse specialists, chaplains, social workers, pharmacists and other appropriate health professionals. Specialist palliative care can be provided at home, including care homes; in hospitals or hospices.

Care, however, focuses on complex needs such as pain management or psychological, social or spiritual needs.

The other category is general palliative care, which is provided during a patient's day-to-day care across all health care settings by his or her usual carers.

A good death

One of the overall aims of palliative care is to provide the conditions for a good death. Although there are inherently subjective elements in what may be said to constitute a good death, the following have been usefully identified:

- being treated as an individual, with dignity and respect;
- being without pain and other symptoms;
- being in familiar surroundings; and
- being in the company of close family and/or friends.

Scottish Council on Human Bioethics Response

In the above list, the following should be added: 'being in a state of spiritual balance.'

Recognised need to improve palliative care services

In recent years the need to improve palliative care has been recognised widely within and outwith Scotland. The previous administration committed itself to the provision of: "*high-quality palliative care to everyone in Scotland who needs it, on the basis of clinical need not diagnosis and according to established principles of equity and personal dignity*".

Internationally, the World Health Organisation published two reports reviewing the scientific evidence on palliative care and recommended that policy-makers:

- develop a strategy to meet the care needs of an ageing population at the end of life, particularly those who are living and dying with a range of serious, chronic illnesses;
- ensure palliative care is a core part of health care services and not an add-on;
- acknowledge people's right to high-quality palliative care, including specialist palliative care and choice regarding place of care and death;
- ensure equity of access to palliative care services.

In England, Baroness Finlay of Llandaff's Private Member's Bill on Palliative Care, introduced in 2006, has received a third unopposed reading in the House of Lords. This Bill has received widespread public support indicating that in England and Wales provision of palliative care is also an issue.

The report *Living and Dying with Advanced Heart Failure* highlighted variations in standards and access to palliative care as a significant challenge faced by patients and carers in cases of advanced heart failure. Moreover, in comparison to those with cancer, patients with advanced heart failure have inadequate symptom relief, a worse prognosis and more limited access to palliative care support, social and financial services. Patients with advanced heart failure are also less knowledgeable about their condition and have less opportunity to address end-of-life issues.

The report also stated there were approximately 100,000 people living with heart failure in 2007, but indicated an expected increase in the prevalence of heart failure by as much as 70% by 2010, due to an increasing elderly population.

In his preface to the report, Dr Harry Burns, Chief Medical Officer for Scotland, said: "*I fully endorse what I think is one of the most important statements in the report: that the inherent unpredictability of the disease is not sufficient justification for a failure to introduce appropriate palliative care to the ongoing management and support of those with heart failure.*" [p.4]

The report concluded that there should be a wider recognition of heart failure as a terminal condition adversely affecting quality of life in order to facilitate better service provision.

Audit Scotland palliative care review

In August 2008 Audit Scotland published its review of palliative care provision in Scotland. The review confirmed that palliative care is primarily cancer-focused and mostly provided by generalist staff in hospitals, care homes or patients' own homes.

However, the report indicated palliative care needs are not always recognised or well supported and suggests support of generalists by specialists would improve palliative care provision for patients and their families.

The review states that palliative care needs to be better joined up, particularly at night and weekends, and that support for family and friends who are caring for someone is not widely available.

Scottish Government palliative care action plan

In October 2008, the Scottish Government launched its *Palliative Care Action Plan* in fulfilment of its commitment made in 2007. The Action Plan aims "*to ensure that good palliative and end of life care is available for all patients and families who need it in a consistent, comprehensive, appropriate and equitable manner across all care settings in Scotland*".

Whilst this is welcome, as is the emphasis on the principles of equality, dignity and quality of care, the Action Plan acknowledges that it:

"... does not yet have all the answers. Living and Dying Well identifies some changes which can be made in the short and medium term, and some which will take a little longer and will require further collaborative and developmental work, as well as additional input of time and resources." [p.9]

The proposed Bill and current Scottish government proposals

Essentially, what the proposed Bill envisages is a significant addition to the measures proposed by the Scottish Government. The Government's proposals are the result of extensive collaboration with stakeholders, which has produced wide agreement about aims and a shared commitment to them. These are substantial and necessary achievements.

The aim of the proposed Bill is entirely consistent with those proposals, but goes a significant step further. The Bill, by placing a statutory duty on NHS Boards to provide high-quality palliative care for all on the basis of need, will raise the priority of palliative care provision and give added focus to efforts to achieve that outcome across Scotland.

A statutory obligation will encourage the necessary co-ordination, training and system design changes, as well as the development of funding streams and reporting methods. It would, therefore, greatly increase the care being delivered as envisaged and bring forward the point at which it would become available.

The proposal will also have the effect of acting to maintain and protect the provision and standards of palliative care across Scotland and put in place a greater degree of accountability than is contained in the Government's proposals. These must be worthwhile objectives for an aspect of health service provision that will only grow over time.

High-quality palliative care: general adoption of good practice

There are a number of good practice initiatives being used to improve the quality of palliative care; these are principally the Delivering Choice Programme, the Gold Standards Framework – including the entry of patients onto the Palliative Care register – and the Liverpool Care Pathway. The overall objective of these initiatives is to offer patients more choice in relation to their health needs, including improving choice and quality of care at the end of life. Specific objectives are to achieve:

- greater choice for patients, irrespective of their diagnosis, where they wish to live and die;
- a decrease in the numbers of emergency admissions of patients to hospital when they wish to die at home;
- a decrease in the number of patients transferred from a care home to hospital in the last week of life;
- to educate and up-skill generalists across health and social care settings in end of life care delivery.

The route to quality care may be different, but by providing some form of measurement it should be possible to monitor care standards across NHS Board areas.

It is my intention therefore to specify within the proposed Bill the type of information, which will allow the Government and the Scottish Parliament to determine whether this aspect of my proposal is being achieved. As such I have drawn up a list of data from which it should be possible to identify whether patients have received high-quality palliative care. For each patient in every health board area, the following information should be recorded and reported to provide an indication of whether high-quality care has been provided:

- place and cause of death;
- how well pain and other symptoms have been assessed, documented and managed, based on evidence-based clinical recommendation;
- the number dying in their place of choice as suggested in the Advanced Care Plan;
- number of out-of-hours emergency admissions at end of life to all care settings; and
- the stage at which palliative care was made available.

These minimum reporting requirements have been chosen as they are measurable and will provide a basis on which NHS Boards can report their progress in meeting the needs of patients who require high-quality palliative care.

Q3 A list of indicators of high-quality palliative care has been provided. What other indicators should be included and why?

Scottish Council on Human Bioethics Response

An additional possible element with respect to the manner in which the pain and other symptoms are assessed, documented and managed, based on evidence-based clinical recommendations, could be the recording of the different kinds of drugs (and dosage) used to address the pain.

For example, a recent study in the Netherlands showed that only 9% of physicians had consulted a palliative care expert which was reflected in around 15% of physicians using morphine without a benzodiazepine to attain sedation. This is in contrast with most guidelines which indicate that morphine is usually rejected as a single therapy to attain sedation because of its unpredictable sedative and side effects¹.

Another indicator which could be considered is the use of Do Not Attempt Resuscitation (DNAR) forms since they fit with advance care planning.

Finally, the indicators should take into account the fact that patients sometimes change their minds at the end and request to be taken into hospital.

Funding

The greatest issue for NHS Health Boards and local authorities will be the funding of palliative care for all patients throughout Scotland.

¹ J. Rietjens, J. van Delden, B. Onwuteaka-Philipsen, H. Buiting, P. van der Maas, A. van der Heide, Continuous deep sedation for patients nearing death in the Netherlands: descriptive study, *BMJ* 2008;336:810-813 (12 April), <http://www.bmj.com/cgi/content/full/336/7648/810>

In 2006, the Scottish Partnership for Palliative Care (SPPC), the representative body in Scotland for palliative care, published the report of its 3-year research project into the issues around increasing access to palliative care for people with life-limiting conditions other than cancer.

The report provided reassurance that the aim of increasing access to palliative care to people with non-malignant conditions is achievable. Consultation responses indicated that much could be achieved “*without making hugely unrealistic demands*” on budgets. Better co-ordination, service design and relatively small changes to working practices could “achieve significant impact”.

According to the Audit Scotland review of palliative care, in 2006/07 £59 million was spent on specialist palliative care in Scotland. Almost half that total came from the voluntary sector. In Audit Scotland’s view, it is not possible to say how much is spent on general palliative care but the review does point out the practical need for NHS Boards and their partners to plan now to meet the predicted increase in demand from an ageing population.

It is recognised that funding and implementation of the Liverpool Care Pathway would also be an issue for a variety of Health and Social Care providers beyond NHS Boards.

It will be for the Scottish Government, in its adoption and implementation of the National Action Plan to consider the budgetary implications of palliative care for both cancer and non-cancer palliative care.

My proposed Bill will underpin the National Action Plan. However, by making it a duty for NHS Boards to provide high-quality palliative care to all who need it, my proposal will have some cost.

Although there is an indication that increased access to palliative care could be achieved without substantial demands on budgets, the Government is providing additional funding. It would be helpful to have some indication of where the greatest costs will be incurred.

Q4 What are the funding implications of this proposal? Please provide detailed costings.

Scottish Council on Human Bioethics Response

The SCHB is of the opinion that the Scottish Government should provide additional funding to palliative care costs. This would also help to support the hospice movement which is very important.

Palliative Care is an important aspect of National Health Service Provision. This Bill may ensure that money could be allocated to Health Boards to provide adequate Palliative Care. This may mean that some funding is directed away from other specialities. However, this would be in keeping with a general move away from surgical interventions and towards a more holistic and caring approach to health.

Accountability

The proposed statutory obligation on NHS Boards to provide high-quality palliative care to those in need should be monitored to ensure that the aim of the proposal is being met. Therefore my proposed Bill will have to set out a mechanism to achieve this.

It is my intention that NHS Boards should report annually on the implementation of their palliative care plans, including the quality of palliative care provided. In addition, the Government should be required to report annually to the Scottish Parliament on the implementation of its national strategy for palliative care. A matter for consideration is whether this is done separately from, or is included in, existing reporting requirements.

Who will be affected by the proposed Bill?

Those who will benefit from the Bill will be patients, their families and carers.

Health and Social Care providers will be expected to comply with the Bill to ensure patients receive access to high-quality palliative care, choice of preferred place of care and staff must be trained to the standards required to deliver such care. Health and Social Care professionals at all levels are responsible for the delivery of end-of-life care and ensuring patients receive equity of access to the highest quality of palliative care in their locality.

NHS Health Boards in each authority in Scotland will have a responsibility to deliver palliative care to patients with all end-of-life chronic diseases and to implement the National Plan in relation to palliative care introduced in October 2008.

This will involve NHS Health Boards working in partnership with the Scottish Government, the Scottish Health Council and Voluntary Organisations to ensure delivery to all people in need of this care throughout Scotland, regardless of diagnosis.

The Scottish Government will be affected by supporting the implementation of the National Action Plan by the need to establish the budget requirements to ensure palliative care availability for all conditions, both malignant and non-malignant.

The Scottish Health Council will need to measure the patient focus/public involvement aspect of target achievement and the collection of good practice examples.

Voluntary organisations will be required to ensure staff are trained in the delivery of palliative care whilst ensuring that patients, their families and carers have access to high-quality palliative care. Voluntary organisations will be expected to work in partnership with the NHS Health Boards and the Scottish Commission for Regulation of Care to ensure that appropriate standards are met.

Q5 What other organisations etc. will be affected by the proposal and in what ways?

Scottish Council on Human Bioethics Response

The SCHB believes that all organisation working with the physical, psychological and spiritual issues associated with advanced disease would be affected by the proposals.

Conclusions

The evidence shows that the needs of people dying with a non-cancer diagnosis and the needs of their families are similar to those with advanced cancer. Nevertheless, only a small minority access specialist palliative care. Indeed, for many people with advanced heart failure, the severity of symptoms exceed those with a cancer diagnosis and their set of needs can be of similar and / or greater complexity.

Recommendations from key documents and the positions of past and present Scottish Governments endorse a wider access to palliative care based on need, not diagnosis. They also endorse the reshaping of resources for all life-limiting conditions, the education and training of all health and social care professionals, the setting of measurable targets and the use of evidence-based care models.

These are not only sensible and humane objectives but will be seen as increasingly necessary as the Scottish population ages. The time to prepare is now.

That is why the proposed Bill places a clear priority to high-quality palliative care provision across Scotland by placing a statutory obligation on NHS Boards to provide it.

Q6 Please provide any other comments on the Bill's proposal to place a requirement on all Health Boards to provide high-quality palliative care to everyone in need of it.

Scottish Council on Human Bioethics Response

- More training should be provided to general health care professionals relating to palliative care.

- The proposed Bill should conform to all the provisions included in the following Council of Europe legal instruments:

- Recommendation Rec (2003) 24 of the Committee of Ministers to member states on the organisation of palliative care.

This was Adopted by the Committee of Ministers on 12 November 2003 at the 860th meeting of the Ministers' Deputies (See: [http://www.coe.int/t/dg3/health/Source/Rec\(2003\)24_en.pdf](http://www.coe.int/t/dg3/health/Source/Rec(2003)24_en.pdf))

- Resolution 1649 (2009) of the Council of Europe Parliamentary Assembly on Palliative care: a model for innovative health and social policies .
(See: <http://assembly.coe.int/Mainf.asp?link=/Documents/AdoptedText/ta09/ERES1649.htm>)

It should be noted that the above Council of Europe Recommendations can be used to 'inform' the decisions of the international judges sitting on the European Court of Human Rights.