Palliative Care (Scotland) Bill

Dr Ronald J Clearkin

I am grateful for this opportunity to respond to the consultation on this Bill. In making my response I have also examined the accompanying Call for Evidence, Explanatory Notes and Policy Memorandum.

The Palliative Care (Scotland) Bill (PCSB) is intended to:

1. enforce equality of access to palliative care across Scotland;
2. raise the profile of palliative care in Scotland;
3. give statutory force in particular to the Scottish Government’s 2008 “Living and Dying Well” strategy. The latter is a comprehensive framework of recommendations and actions requiring implementation by the Health Boards amongst other groups by June 2010;
4. require yearly submission of numerical data outlining the numbers of patients and their families receiving palliative care in each Health Board to the Scottish Ministers who in turn will report to the Scottish Parliament.

It is acknowledged that the National Health Service (Scotland) Act 1978 includes, in Sections 36 & 37, general duties obliging the Health Boards to provide care which could include palliative care, though this is not specifically named. Duties under this Act require Health Boards to provide the full range of therapeutic interventions without their specific identification, hence for instance, new therapies for acute stroke or interventional radiology, without which much of modern medicine would cease to be practised, are not specifically named yet are provided to a high standard in Scotland. While inequity of provision may initially occur, the mutual nature of the NHS in Scotland and the general duty on Health Boards would achieve fair distribution across all communities.

Since palliative care is already well known and highly appreciated in communities across the country, it is hard to see how its already high profile could be further raised by this Bill. In 2008 the Scottish Government published its “Living and Dying Well” strategy, obliging all Health Boards to undertake and complete a wide range of actions by June 2010, to realise its strategic ambitions. It is difficult to discern therefore what more would be achieved in laying statutory duties on Health Boards, duties which they appear capable of assuming and maintaining without legislative coercion.

High quality specialist palliative care is undoubtedly one of the great advances in medical care of the last fifty years. All practising physicians and their patients have cause to be grateful for the advice and assistance of specialist palliative carers. It is not at all apparent, by contrast, that with only a little extra training in palliative care, any “generalist” could provide the same range of care options and depth of knowledge possessed by specialists in the field. Yet the drive to increase palliative care provision through the “Living and Dying
Well” strategy and the PCSB will by design increase only this “generalist”, non-specialist care, which is likely therefore to fall well short of best possible care. Furthermore, with no additional hospice beds and hospital admissions effectively barred, this care will have to be provided in the much less than optimal setting of the patient’s own home or a care home.

It is no exaggeration to state that very large numbers of patients who choose or are anyway obliged to spend their last weeks or days of life in the community will be put at increased risk of premature death by these reforms since:

(i) it is hard to perform comprehensive clinical examinations in a community setting, particularly against severe time pressures;
(ii) because there are no diagnostic facilities in these locations and hospital admissions must be avoided, readily treatable and reversible causes of deterioration will often be missed. It must be emphasised that not all deteriorations, in the elderly for example, even the most seemingly severe, necessarily indicate that death is imminent, and simple interventions often have dramatic benefits;
(iii) regular turns for comfort or to prevent pressure sores and fluids given by the subcutaneous route are among the simplest and most basic types of care. If even this level of care cannot be provided safely and reliably, then care homes and patient’s homes must not to be used. Nor, it must be noted, do many care homes have a reputation for offering so much as ordinary care, reliably or adequately. How then can they be expected then to competently and humanely care for what will be the large numbers of elderly persons dying in their charge?;
(iv) rather than a range of therapeutic options administered under the supervision of experts, the sole “palliative care” option in the new strategy for Scotland is effectively the Liverpool Care Pathway for the Dying (LCP). This highly controversial pathway has received a great deal of serious criticism over recent years. Despite periodic tweaks to produce newer versions, the basic structure and assumptions of the LCP remain unreformed and render it inherently unsafe in the view of many well informed critics. Key weaknesses include an inadequate basis for making the all-important diagnosis that death is imminent, exclusion of reversible causes of clinical decline is readily skimped or ignored, and it can be started by anyone, even the least experienced and most junior members of a clinical team. Idiosyncratic, “ageist” or other discriminatory criteria for commencing the pathway seem rife, and once begun, patients die in a median time of only 33 hrs. Relatives are frequently unaware that the pathway has been started and the much vaunted “spiritual” support for both patients and next-of-kin is almost non-existent as evidenced by national audits of the LCP. Patients are routinely denied knowledge of their diagnosis or the fact that they are dying. In practise therefore the LCP seems
to embody an approach to patient’s rights that most patients and healthcare staff would have hoped was long gone;

(v) non-cancer diagnoses account for 70% of deaths across the UK yet there is no scientifically validated means of predicting death in this large group. Even in cancer, which has been far better studied, prognoses are frequently wrong\textsuperscript{8,9}. Use of the LCP in non-malignant conditions is posited on models of illness “trajectory”, though the impossibility of predicting which particular episode of deterioration is truly terminal is a fundamental and major weakness. Despite this absolute lack of prognostic ability, application of the LCP to non-cancer diagnoses is enthusiastically promoted. “Living and Dying Well” is unfortunately no exception to this and unfortunately the PCSB would give it statutory force. This must be deprecated.

(vi) the “Gold Standards Framework” (GSF) suggests diagnosis of decline based on “instinctive and “insurance type” thinking\textsuperscript{10}; I suspect studying tea-leaves would be as accurate, but then neither proposal is supported by scientific evidence and each is likely to deprive patients of months or even years of valued life.

It seems moving care to often deprived settings in the community “, trawling rehabilitation and continuing care wards for candidates\textsuperscript{11}, diagnosis based on “instinct” and prejudice rather than the usual evidence-based and rational means, the “anticipatory” stockpiling of drugs\textsuperscript{12} and syringes in homes and in care homes (will this lead to break ins by drug addicts?), draconian requirements to avoid hospital admission for any persons who it is guessed might die in the next 12 months (with compulsory reports to Scottish Ministers on those who are admitted under the Bill), rapid death by syringe driver without irritating delays to exclude reversible causes of deterioration, will all become the norm. This model is cheap, it does not rely on expert care such as we all would rightly expect for the management of any other clinical problem, and it will be carried out without such peer supervision as would occur in a hospital setting. The opportunities for abuse are obvious.

So why is a coercive, legislative approach to this area being proposed when in the first place it seems unnecessary, and in the second there are serious risks to patients? One significant pointer is provided by the abstract quoted in the Explanatory Notes to the Bill:

“...palliative care in hospitals is associated with significant reductions in per diem costs and can generate significant savings to the health system by “cost avoidance”\textsuperscript{13}.

In other words active and often expensive treatment and costly investigations stop once palliative care becomes the dominant approach to the patient. The earlier this approach is adopted therefore the greater the avoidance of costs. The financial rewards of such an approach make it dangerously attractive in these straitened times. Much is made of patients “choosing” to die at home, but there is little point in giving legal force to “patient choice” when patients do not appear to have been made aware that palliative care will be downgraded
from specialist care to the “generalist” or amateur kind, and that access to diagnostic and supportive care is to be drastically curtailed. I suspect that, correctly informed, few patients would choose to be less well cared for, even if this meant they could die at home.

The Palliative Care (Scotland) Bill represents a lost opportunity to increase provision of specialist palliative care to the people of Scotland through the funding of more training posts, and the expansion and integration of the hospice model into the NHS. Such measures would undoubtedly raise the profile of palliative care, increase the quality of palliative care provision, and, hopefully, permit a greater availability of respite care for both patients and their carers.

I feel also that the reporting requirements of the Bill unnecessarily breach the medical confidentiality of patient and next-of-kin alike, in requiring seemingly unanonymised information on such matters as psychological/psychiatric support, and the nature of any spiritual support provided. Furthermore there are no denominators to give scale to the numerical data demanded, which are in any case excessive being to 7 generations of those families who receive palliative care. The detailed reporting requirements seem to illustrate the common but unfortunate error of confusing targets with standards.

The Bill seeks to promote an all-encompassing but inherently unsafe standard of care. Since it seems to me neither necessary nor beneficial I therefore oppose it as a whole.

Dr Ronald J Clearkin BSc MB BS MRCP FRCA
Consultant General and Respiratory Physician (Retired)
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5 Personal communication, Julia Quenzler of “SOS NHS Patients in Danger” in meeting with Dr Teresa Tate & others, National Council for Palliative Care, London, 3 December 2007.


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8 “A strategy for end of life care in the UK”. Julia Riley (“It is difficult to define exactly when end of life care starts and even more so to predict prognosis accurately”) BMJ Editorial 2008:337: p185-186 (26 July 2008)

9 National Care of the Dying Audit – Hospitals (NCDAH); Generic Report 2006/2007 p23 (“…it is important to remember that diagnosing dying remains a clinical challenge and more research is urgently needed to identify those signs and symptoms that indicate approaching death.”) (www.mcpil.org.uk - last accessed 7.2.2008)


11 Living and Dying Well: a national action plan for palliative and end of life care in Scotland; Example 13 p.30 http://www.scotland.gov.uk/Publications/2008/10/01091608/0


13 Cost and Non-Clinical Outcomes of Palliative Care
Thomas J Smith, J Brian Cassell
Quoted in: Palliative Care (Scotland) Bill, Explanatory Notes (and other accompanying documaents) Para.77 p.13

14 Palliative Care (Scotland) Bill 2010, Schedule 9A, Indicator 9

15 Palliative Care (Scotland) Bill 2010, Part IIIA, Section 48C, “family member”