

We need to talk about Palliative Care

Church of Scotland's Church and Society Council

General Comments

The Church and Society Council of the Church of Scotland believe that the provision of good quality palliative care is an essential part of the holistic approach for the care of those with terminal conditions. Through our 800 parish ministers, located in every part of Scotland, as well as through specialist healthcare chaplains and thousands of our members involved in pastoral care we have a unique insight into the care of those struggling with deteriorating health and striving for dignity in life. Through this role, offered to every person living in Scotland, we not only offer spiritual comfort to those coming towards the end of their lives (and their families) but we also, with others, seek to ensure that their last days are as fulfilled as possible.

Decision making at the end of life is not done in a vacuum, but involves wrestling with ethical issues around a time of death. This is done by patients, clinical professionals, carers and relatives who all bring their own life experience, values, beliefs and feelings to the decision-making process. This takes place in a specific context involving a unique patient with a disease or injury presenting itself in a particular way. Good palliative care is a critical part of that mix.

For us, death and dying have pastoral implications which are spiritual (including an impact on beliefs and values, as well as raising 'why' questions) and psychological – for patient, relatives and staff. The death itself, the manner of the death, or the continuing survival of a patient and their subsequent quality of life are significant, as is the decision-making process, and by whom decisions are made.

We welcome the decision of the Health and Sport Committee to hold an inquiry into palliative care in Scotland and are pleased to be able to respond.

Questions

1. What has been your experience in terms of access to palliative and end of life care?

The Church, through ministers, chaplains and others involved in pastoral care, provides spiritual care to people throughout their lives including accompanying people with terminal illness as they prepare for the end of life. We operate in every part of Scotland, and we are there for everyone living in Scotland not just for our 400,000 members.

In our submissions to the Scottish Parliament, most recently in the 'Assisted Dying (Scotland) Bill', we have advocated increased investment in palliative care alongside more consistent standards of provision across the whole of Scotland. Scotland provides world class palliative care but it is not currently as accessible as it should be to all of our citizens, regardless of the disease from

which they are suffering, where they live and how old they are. The whole focus of “end of life” care should not just be on the moment of physical death, but on the period (days, weeks or months) leading up to that event, with the emphasis on achieving the best quality of life possible. The focus should follow the palliative care model of holistic care – physical, psychological, spiritual, and social – with positive objectives which will enhance the remaining days of the patient, and of relatives and carers. This is true “dignity in dying”.

2. How could it be ensured that access to palliative and end of life care is equitable and available in all areas and for all types of terminal illnesses?

The provision of palliative care across Scotland to people with all types of terminal illness requires an increase in the number of specialist trained staffs including doctors, nurses, physiotherapists and chaplains who are able to travel to the patient. This should include seeing patients at home, in a GP surgery, acute hospital, care home etc. It may not be realistic for general health and social care staff to be trained up completely but specialist staff can teach and advise “on the job” on a case by case basis without taking over the patient care or admitting the patient to hospice or similar institution. The Church of Scotland already plays a crucial role in community-based palliative care and is committed to identifying ways to increase and extend this service.

Clinical nurse specialists (CNS) in all areas of cancer and non-malignant progressive illness are an excellent resource for patients. All people and families should have access to such nurse specialists and those nurses should have intensive training and links with palliative care specialists. At present this works better for cancer than other conditions and general frailty. We would strongly advocate that the level of palliative care currently available to cancer patients be extended to others approaching the end of their lives.

The provision of Hospice Care, as part of the package of palliative care available is not universal across health boards with some, like NHS Fife providing it as part of the NHS provision and with hospice beds (and wards) located in or on other hospital sites. Core funding for these is taken from the Health Board budget and augmented by charities such as Macmillan. In other areas provision is more usually by charitable institutions, with whom Health Boards contract for services. The question therefore for Scottish Government is now do they ensure equity of availability and of standard of provision in such a mixed economy?

3. Can you identify any areas in terms of access to palliative and end of life care that should be focused on as priorities?

There should be an increase in staff in acute hospitals, both outpatient and inpatient as this is often where the diagnosis is made and bad news is given. If palliative care nurses and doctors were able to connect with people with their relatives and loved ones straight from the clinic or ward where they have been diagnosed and then pass them on to an appropriate level of follow up then the whole progression of a serious illness could be less daunting. This

could include dementia clinics, respiratory, heart failure etc. rather than focussing on cancer as at present.

We would urge that every effort be made to improve access to spiritual care through chaplaincy services as this is an essential part of end of life care for many patients and their families.

In our work we repeatedly identify the need for consistent messages and personnel when communicating to people at very vulnerable times in their lives. Particular care is required for those without family and friends in attendance.

4. When is the right time to begin discussing options for Palliative Care, who should be party to that discussion, who should initiate it and where should it take place?

Our experience is that there is a need to adopt a strongly person-centred approach. The right time is different for every person affected by illness. The right place will also vary depending on the individual. It may be unhelpful to attempt to make an “efficient” system of triggers (which, as the Liverpool Care Pathway illustrates, can have a tendency to degenerate into “tick box” exercises over time) at any particular point. Harm may be done to someone who is not ready or interested in what can be painful discussion, even when done as sensitively as possible.

It takes skill and experience to know when to push these discussions if the patient appears to be avoiding them. It may be best to do nothing other than be there as a good listener, and to offer open access for any questions regarding help and care. These are areas where pastoral and spiritual care is especially important.

In addition, we feel we should avoid systems such as the GP being rewarded for noting down the preferred place of death – when the patient still wants to live and cannot contemplate this choice yet – and the hypothetically chosen place of death may not actually prove to be an option anyway.

Nonetheless, there are some important principles which our experience would suggest, including:

- Wherever possible the patient should be accompanied by a relative or close friend;
- People should be encouraged to write down the essentials of the conversation;
- The initial conversation should be followed up with another meeting, ideally with the same people present, to ensure that any questions are able to be addressed.

5. What works well in discussing palliative and end of life care and how is good practise communicated? Where do the challenges remain?

While some aspects of good communication are difficult to teach, all staff can benefit from training. The challenge is the huge number of professionals and the other demands on their time. Palliative care training courses are appreciated by health and social care staff but we still need specialists on the ground to back up their learning with case by case discussion.

6. What is the role of anticipatory care plans in supporting Palliative Care discussions and how can their uptake be improved?

They can be useful – but again they need to be introduced with skill and sensitivity and can be very time consuming. Families may know better when to introduce these than medical staff.

7. How should information about Palliative Care be made available to patients and their family during any initial discussions and how easily available is this information?

See our response to question 2 – if integrated into the care offered in all areas and for all conditions, palliative care could be seen as part of the medical/social support given to us all when we become less than fully fit and healthy. Most chronic conditions have associated symptoms. When these conditions are incurable and have the potential to shorten life expectancy then the care providers should have a general awareness of the need for symptom control and planning for future care needs, rather than leaping straight to planning for the death of a person- a trajectory which can be very difficult to predict.

8. What training and support is provided to Health and Care staff on discussing Palliative Care with patients and families and are there any areas for improvement?

The term “palliative care” is often associated with dying and with cancer. There are various initiatives to improve understanding at undergraduate level and also once in training. However as suggested in our response to question 2, support and education is best delivered in the ward/clinic/home during the care of real people, and hopefully experience and confidence then grows.

9. How do Health and Care organisations ensure that the discussions about palliative and end of life care are taking place at the right time?

Discussions about end of life care need to be handled with sensitivity; this may require extra time for the consultation. If health care workers are too rushed, then patients and families will suffer from a lack of information or too much information before a person has understood and come to terms with the meaning of a diagnosis, which then has the potential to cause distress.

10. What are the challenges in recording and documenting Palliative Care priorities and how well are those priorities communicated between different health and care providers?

There are big challenges here. There may be electronic records held in the community and available to acute hospital staff which are designed to provide this information. However the completeness of information within them, and the use of them even once complete varies across and within Health Boards. Improvements can clearly be made.

Patients can carry their own advance care plan with them but not all patients will do this and some are not aware of this option. In hospitals there are initiatives such as Ceiling of Treatment forms which can be used to record the level of treatments which a patient could tolerate and benefit from and which are designed to avoid futile or harmful over treatment. This process can open up important lines of communication and help people to understand that there is a limit to what can be achieved through medicine and there is a time to make choices about other more important matters.

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