

We need to talk about Palliative Care

Friends At The End (FATE)

About FATE

This submission is written on behalf of Friends At The End (FATE), a members' democratic society dedicated to promoting knowledge about end-of-life choices and dignified death. We run a befriending service for those with terminal conditions to ensure they are able to receive the proper emotional and medical support to allow them to make choices to allow them to enjoy a good, compassionate and dignified death.

Our submission is based on the experience of our members which includes retired and practicing doctors with extensive experience in palliative care both in the UK and abroad.

Specific answers

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

There is substantial variation in availability which, unfortunately, does not appear to be improving. Although most terminally ill patients want to die at home, many who wish to be admitted to a hospice are unable to do so due to a lack of places. This is particularly difficult to achieve when a crisis arises. An urgent admission to a general medical hospital ward has then to be arranged as an alternative, an outcome which is frequently unsatisfactory.

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?*

Within primary care the funding of GPs and District Nurses (DNs) does not reflect the time and skills required to do this well. It also depends on how motivated the team are to provide it. Those GPs who are comfortable with palliative care are more likely to do it but those who are less enthusiastic are not incentivised financially to do it. This does not mean financial reward should be a driving force but, equally, it should be reflected that this is a particularly challenging area of medical practice and doctors and nurses need to be rewarded for their time and skills.

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

Given that most patients consistently wish to end their days at home, it would seem more important to increase the numbers of domiciliary care staff, rather than build more hospices. Imaginative developments should also be considered. Those could include pilot studies which assess the impact of payments to GPs for delivering good palliative care.

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?*

Ideally, this should be initiated by the patient; in practice, that is rare and care staff have to remain alert for “cues” from the patient that such discussions would be welcomed. For patients at home, that could mean a health professional, most often the GP, DN, Specialist Nurse or possibly a combination of all three. If the patient has mental capacity, then anyone else they wish to be present should be included. If they are losing capacity, whoever holds Power of Attorney also needs to be involved in important decisions.

However, before those discussions can begin, the doctor needs to acknowledge cure is no longer an option and the trajectory of the illness is proceeding inexorably downhill. Although it does not feature in ICD-10, the 10th revision of the International Classification of Diseases, one of the most useful and compassionate diagnoses a doctor can make is that the dying process has started. This should not be confused with an estimate of life-expectancy, nor need it prevent palliative treatments, including chemotherapy and minor surgery. It does, however, allow any diagnostic and therapeutic endeavour to be measured against the question, “Will this usefully affect the inevitable out-come?”

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

What works well?

Open questions that seek patients’ thoughts e.g. “*If your time is short, what are your priorities and how can I help you achieve them?*” How much do you wish to know - everything, or just what you need to know? What do you want me to tell your family and do you wish me to answer all their questions, including ones you may never ask?”

Challenges:

- (1) Time pressures. Good-quality care takes time. Giving patients the opportunity to talk, voice their fears and raise questions cannot be rushed.
- (2) Out of Hours continuity of care. The fragmentation of community care, with the involvement of multiple agencies and professionals who work part-time means this is difficult to achieve. The relentless and unsustainable increase in the workload of GPs means that is irreversible. Arguably, this is the biggest inhibition to the delivery of good quality palliative care. If it is to be given the prominence it deserves and patients’ desire, then something else within general medical practice has to give way to allow that to happen.
- (3) Integration of palliative care with assistance in dying. Although the Assisted Suicide (Scotland) Bill recently failed to gain majority support

from MSPs at Holyrood, in the longer term there is little doubt the issue will return to Parliament at some point in the future. Experience gained elsewhere in the world, including Oregon, shows the introduction of assistance in dying can be followed by improvements in palliative care¹. Perhaps most usefully, and recently, in Quebec a law giving its citizens the statutory right to both measures, in addition to making advance directives legally binding, has recently been introduced.²

Although the wisdom of continuing to separate these matters is questionable, later this year the Lords will debate an Access to Palliative Care Bill while the Commons will discuss an Assisted Dying Bill. There is a need to accept both aspects of care can comfortably co-exist, without the one necessarily compromising the other.

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

These can be helpful in passing on clinical information to other agencies, including NHS 24, when GP's are unable to be directly involved in care. At present ACP's are more likely to be used in palliative care than anywhere else. This could be further improved by paying GPs to under-take them for a high percentage of their palliative care register patients. A feedback mechanism from those who use them should also help to improve their quality.

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?*

Written material given by DNs or specialist nurses during consultations, backed up by good websites can be helpful. However, such leaflets can be rather "mechanical" and discussing matters "face to face" can often be more satisfactory.

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

Training in palliative care is widely available, although attendance at such events is optional for GPs and likely to be chosen only by those with an interest in the field. We believe it may be beneficial to make some level of basic training a mandatory measure which requires to be updated over a period of time.

¹ <http://reportcard.capc.org/home/OR/RC/Oregon>

² www.mourirdansladignite.gouv.qc.ca

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?

The approach to this varies widely. It is laudable that some GP groups use regular monthly palliative care register meetings with DNs and Specialist Nurses to share information and coordinate care plans for individual patients, while others do not and appear to work in isolation.

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?

(1) Individual patient's perspective: It can take a long time for a GP to properly carry out a palliative care home visit in the middle of a busy day, then enter a computer record of the consultation, prepare DNA CPR forms and adjust "Just in Case" medicines. Time is also required to speak to colleagues and have Gold Standard meetings - these crucial meetings are often not factored in when carrying out DNs job planning and funding GPs. The IT skills and software linked to this aspect of palliative care need to be excellent; they need to work at both the user and reader ends.

(2) National strategic perspective: A recent comprehensive review conducted by the London School of Economics on behalf of Marie Curie estimated that 10,600 people in Scotland were currently being denied access to palliative care³. It estimated that annual savings of more than £4 million would be achieved were this to be introduced throughout the country. It also identified particular problems with non-cancer care; the very old; ethnic minorities; the poor; certain geographical areas and those who live alone. This information was obtained from a National Survey of Bereaved People carried out in England and Wales by the Office for National Statistics (VOICES), 2013. Just how appropriate it is to extrapolate its findings north of the border remains unclear. A similar survey has never been conducted in Scotland but the Committee and NHS Scotland would benefit greatly were such a study to be undertaken here.

Conclusion

We hope this information is of use to the Committee as it debates and discusses this vital subject. FATE would be happy to be called to give oral evidence or provide additional information in writing if that would help Members in their work.

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³ Dixon J, King D, Matosevic T, Clark C, Knapp K (2015) Equity in the provision of palliative care in the UK: review of evidence. Personal Social Services Research Unit, London School of Economics and Political Science, London.