

Identifying end of life patients benefits us all - plan ahead to avoid crises

Caring for a patient right through to the end of life can be one of the most satisfying aspects of general practice, but it is also one of the most challenging roles we face.

As gate-keepers to health services, if we do not plan community support for terminally ill patients, they will end up in crisis using emergency services and being admitted to hospital when they don't want or need to be there.

Typically in the last 12 months before death, patients average 3.5 admissions each, with estimates that at any one time 20% of all hospital beds are occupied by people who are dying. Unnecessary admissions and lengthy hospital stays can be avoided by effective advance care planning.

Many of us have been working hard to find the 1% patients¹ likely to be in the last year of lives, but this is not easy, particularly when identifying non-cancer patients. Research shows that most people with a non-cancer diagnosis are not identified for palliative care before they die and miss out on the benefits of symptom relief as well as social, psychological and spiritual support. This is because people with cancer are generally well-served by palliative care services. Better and earlier identification of all patients who may benefit from these services is vital so that they can receive the care they need, and not slip through the net.

This is why I think it might be more realistic to identify patients in their last years of lives, particularly those patients with progressive, life-limiting illnesses, who experience longer and unpredictable trajectories of decline. Interestingly, a recent paper in the European Journal of Palliative² concluded that a gradual and long term approach to phasing in supportive and palliative care while continuing with other treatment care planning would benefit patients and their families.

We know that some GPs find it difficult to raise and discuss death and dying with patients, but having these difficult conversations is a fundamental part of advanced care planning and supports positive patient (and carer) experiences at the end of life. Talking more openly about death and dying with our patients and their families, also enables them to have a better understanding of what lies ahead and have time to deal with the news and realign their priorities. It also ensures they are provided the support they need when making important decisions relating to their future care needs. Greater openness will also help patients to live as well as they can in the last years, months, weeks and days of life.

In order to effectively identify and support patients we need to use locally developed tools to proactively manage care. Many areas have already developed or are in the process of developing electronic palliative coordination system (such as EPaCCS / KIS). Whilst there are challenges regarding different operating systems and how they 'talk to each other', electronic information sharing is vital.

There are many benefits to utilising locally developed tools:

- potential to share information regarding patient wishes and key elements of care and planning

- shared information is vital for working with OOHs services and Acute Trusts
- reduces the need for patients to tell their story again and again (although doesn't replace clinical review and assessments)
- provides a framework for care planning discussions that puts the patient at the centre
- provide a care pathway that enables health professionals to put the patients at the centre of health care delivery
- is designed to facilitate and strengthen communication across care settings

It is in everyone's interest to use electronic information sharing tools. The evidence is clear and strong. Using electronic palliative care co-ordination systems effectively will support people's wishes to be cared for and die where they normally live; as well as reduce unnecessary hospital admissions and costs.

We only have one chance to get it right – using these tools will help.

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References

1. <http://dyingmatters.org/gp>
2. Zheng L, Finucane AM, Oxenham D, McLoughlin P, McCutcheon H, Murray SA. How good is primary care at identifying patients who need palliative care? A mixed-methods study. *European Journal of Palliative Care* 2013; **20**: 216–222.

An abstract of the report on www.ejpc.eu.com

Useful resources

- The RCGP has developed the Gold Standards Framework Identification Toolkit to help identify terminally ill patients. Not only does it boost the chances of early identification, it can help determine what stage the patient is at through the prognostic indicator guidance (PDF) tool.
<http://www.goldstandardsframework.org.uk/cd-content/uploads/files/General%20Files/Prognostic%20Indicator%20Guidance%20October%202011.pdf>
- The Scottish Palliative Care Indicators Tool (PDF) is a handy one-page holistic guide to prognostic indicators.
<http://www.scotland.gov.uk/Resource/Doc/924/0111396.pdf>
- The latest comprehensive clinical guidance for identification from RCGP and other end of life resources for GPs. <http://www.rcgp.org.uk/clinical-and-research/clinical-resources/end-of-life-care-resources-for-gps.aspx>
- Economic evaluation of Electronic Palliative Care Coordination Systems.
<http://www.england.nhs.uk/wp-content/uploads/2013/05/economic-eval-epaccs.pdf>