

Never the right time:

advance care planning with frail and older people

*'... the doctor has the map and the patient does not. In fact the doctor not only has the map but drives the vehicle and the patient may not know that they have reached a crucial crossroads, or that they have reached the end, until they get there and it is too late.'*¹

INTRODUCTION

Care of the dying is inadequate in many developed countries, and its improvement is an important national and international challenge. Around 500 000 people die in England every year, of whom 53% die in hospital even though 63% indicate a preference to die at home.²

Although palliative care services have been available for many years for people with cancer, most people do not die of cancer. Other conditions, including multimorbidity and extreme old age, tend to have a less predictable course and such patients are less likely to be found on a GP's palliative care register.

Do older patients really have a voice when it comes to planning their future care? In the first ever systematic review of attitudes of the public and healthcare professionals to advance care planning, Sharp *et al* find there are some critical barriers to be overcome if we are to translate the concept of 'advance care planning' from its origins in palliative care for cancer to frail older people who are dying.³

We know what we 'should be doing'. Why aren't we doing it? In this editorial we examine the opportunities and challenges of advance care planning in the context of a much needed national conversation about death and dying.⁴

WHAT SHOULD WE BE DOING?

Advance care planning is defined as the 'voluntary process of discussion and review to help an individual who has the capacity to anticipate how their condition may affect them in the future and if they wish, set on record their choices about care, treatment, and future decision making'.⁵ It is step 2 of the national end-of-life care pathway after recognition of the dying patient.⁶ The NICE quality standard for *End of Life Care for Adults (QS13)* states the importance of a comprehensive holistic assessment that includes a personalised care plan.⁷

The national primary care audit of end-of-life care showed that patients who had an

assessment with care planning had better outcomes and were more likely to die in their preferred place of care.⁸ However, it was also found that GP registers were incomplete and mostly made up of patients with cancer.

GPs in the UK, because of their unique role of holding the lifelong medical record and having a registered list of patients, are ideally placed to recognise 'transitions' and triggers that indicate that a patient may be dying, such as repeated unplanned hospital admissions and new diagnoses of life-limiting illnesses. Every contact is therefore an opportunity, if appropriate, to consider if the patient is in the last year(s) of their life and to discuss advance care planning.

A Cochrane review recently found strong evidence that the majority of people, in countries for which there is evidence available, express a preference to die at home; this includes patients who have advanced disease.⁹

WHY AREN'T WE DOING IT?

The *Dying Matters* project¹⁰ found that the barriers for GPs in advance care planning include lack of confidence in initiating and maintaining conversations, lack of time, fear of upsetting patients, and lack of certainty about prognostic indicators.

In a systematic review of attitudes to advanced care planning in older patients with no specific diagnosis, Sharp *et al* report a range of barriers, including a passive expectation on the part of the patient that 'someone else will decide'.³ With so much potential for confusion, it is little wonder that doctors and patients hesitate to begin the conversation. We need a deeper understanding of the nature of the relationship between clinicians and patients and greater recognition of their mutual fears.¹

Recognising that we are stuck in relationships that do not meet current needs and which disadvantage patient and doctor alike is not easy. The dominant powers and logic of any system may not even see the problems or recognise them

as significant. It can be hard to admit that guidelines and protocols, designed to reduce organisational anxiety, can also increase the doctor's consultation anxiety, through fear of professional humiliation if they do not adhere to the plan. In a risk-averse culture it can be difficult for doctors to let go of their sense of responsibility and hand the map to the patient.

ENABLERS

If GPs are to make advance care planning routine, raising the topic of death must become as normal as discussing smoking cessation. GPs need practical resources to increase professional confidence such as a 'core' script of words and phrases to use. The discussion of the plan must be focused and brief, and might be supported by paper- or web-based information. Once clinicians are comfortable with their communication on advance care plans, they will be more likely to identify patients in consultations.

Practice teams will need a lead clinician who monitors the success of the strategy and who is sensitive to the human concerns that will inevitably get in the way of its implementation. Clinical commissioning groups (CCGs) will have a role to play as well, by providing local leadership that highlights the importance of advance care plans, and promotes appropriate training, support, and networking. The development of responsive and high quality 24/7 community support services is also essential to help the GP to manage the extra patients they have identified.

The recent review of the Liverpool Care Pathway suggested that many of the problems occurred because of a rigid and unthinking approach to the implementation of the framework.⁴ This offers important lessons. Turning a 'good idea' into a set of guidelines can facilitate its adoption and dissemination through normative and regulatory institutional processes.¹¹ However, the same processes can also distort the ordinary humanity of the doctor-patient relationship.¹ If we wish to change a system, we need to start with its principles

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and values. Negotiating the ‘wicked problem’ of advance care planning is not about changing structures but changing relationships.^{1,4}

ASSISTED DYING

In this issue, Donker *et al*² discuss the Dutch use of palliative sedation at the end of life for refractory symptoms. They report that older patients and those with cardiorespiratory disease are less frequently involved in the decision to use this controversial treatment. While the trajectory of life-limiting non-cancer diagnoses, including frailty syndromes, are predictably unpredictable, Donker *et al*² give ‘sudden deterioration’ as the probable rationale for the relative lack of patient involvement.

In a qualitative study, also from the Netherlands and in this issue, van der Kallen *et al*³ used vignettes to explore attitudes of the Dutch general public towards ‘palliative sedation’. The authors stress that ‘palliative sedation’ should be ‘considered a last resort intervention in end-of-life care’ and ‘should not be confused with euthanasia’. Interviewees considered the patient’s suffering and wishes to be more important than adherence to guidelines regarding the life expectancy of a patient. In the Dutch context, in which euthanasia is a legal option, the ‘varying expectations and attitudes’ towards assisted dying appear to have added to the potential for ‘misunderstandings’¹¹ in end-of-life care.

A request for assisted dying is sometimes ‘a cry for help’ with fear of distressing symptoms such as choking or uncontrolled pain. The wider use of advance care plans — early in the course of illness before capacity is lost — can help mitigate ‘misunderstandings’ in end-of-life care. It is important that concerns about assisted dying do not overshadow the need to improve patient access to high quality palliative care, including opportunities to plan their care in advance.

CONCLUSION

Advance care planning is widely recommended by professional, regulatory, and NHS institutions but it is still not in common use. This translation gap must

be closed. The routine use of advance care planning has the potential to co-create a new model that will shape widespread good practice across many elements of the NHS. The question is: where is the leadership for this going to come from? Are GPs best placed to make this happen when empowering the patient voice threatens our own position as the expert in the room? Re-visioning the patient–doctor dynamic requires a systematic understanding of the barriers to beginning conversations about advanced care in frail and older people⁴ and to use this knowledge to reduce fear. Opportunities to test out different ways of raising and discussing the issue are needed. A powerful stimulus to change would be patients taking the lead and requesting advance care plans.

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Competing interests

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