Clinical decision making in dementia:

mapping the minefields

There is a scene in the 1970 World War II film *Kelly's Heroes* when our platoon of heroes is seen ambling across a peaceful rural countryside. Suddenly the lead soldier steps on a mine. A routine stroll has changed into survival in the middle of a minefield. How will they navigate a safe path out? How will they cope as the inevitable enemy troop lorry approaches?

Clinical decision making at the end of life for care home residents with advanced dementia can be problematic. A stable situation, a routine medical stroll, can turn into a minefield if a critical clinical decision must be made in a rush. One hopes that Do Not Resuscitate (DNR) decisions will usually already be recorded but even this is not always the case. There are of course more everyday decisions about escalation of care in response to exacerbations of chronic conditions or acute presentations such as serious infections. We may be faced with a decision whether to admit to hospital or to provide appropriate medical intervention including symptom control and nursing care in the residential home.

IN WHOSE BEST INTEREST?

Since 2004 the UK Department of Health has had an explicit aim to reduce acute admissions.¹ But Harrison reminds us not to 'assume that fewer admissions or referrals are necessarily better'.² We may feel an ever-increasing pressure from such policies. Admission avoidance may be reflected in local Directed Enhanced Services (DES) often lacking evidence of patient benefit. The 2010 King's Fund report *Avoiding Hospital Admissions* advocates:

*'... proactive management of people with long-term conditions, especially people with complications that arise from having several conditions.'*³

This holds out the promise that with better planning we can avoid admissions, and yet the evidence to back this assertion seems doubtful.⁴ The main evidence supporting admission avoidance in the King's Fund report comes from US models of care that may be driven by cost, rather than evidence of patient benefit. So is our priority to avoid hospital admission or to work out what is in the patient's best interest? And there is always the worry of a troop lorry full of lawyers approaching if anyone thinks we

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have got the decision wrong.

So how do we judge what options are in the patients' best interests? Many of these patients with advanced dementia and at the end of their lives will lack capacity for complex medical management decisions, although this will need to be assessed. What do we know about the patients' prior values and wishes? How many will have left advance directives, and for those that have, how many will remain valid representations of their wishes? We do know that vulnerable patients and patients with dementia often suffer fear and anxiety from hospital admission.⁵ Death during or following an unnecessary ambulance transfer is rarely peaceful and dignified. And we need to be realistic about the burden of treatment itself when such patients actually have little to gain from medical intervention.⁶ The UK General Medical Council guidance is helpful here in supporting advance planning to:

*'... ensure that the patient's last hours or days are spent in their preferred place of care by, for example, avoiding emergency admission from a community setting to hospital.'*⁷

NO PATIENT IS AN ISLAND

But we are then faced with the interests of the other stakeholders, primarily the patients' relatives and the staff caring for them in residential homes. Will the relatives agree? How do we manage if they do not, or if their view seems to us to be against the patient's best interest? Will the front of house policies of the homes survive the day-to-day pressures of the stressed, anxious, and low paid care workers who are closest to the patient?

As GPs we are used to working within a biopsychosocial model. We are also used

to working in teams. Both our model and our teams may be tested to destruction by best interest decisions for such vulnerable patients. Medical life runs most smoothly if straightforward biomedical pathways are enough. Care home staff may well feel less able to cope and more vulnerable to criticism than trained healthcare staff. If we compound medical uncertainty with team conflict then we are in difficulty. Can we find appropriate guides to action?

FINDING THE RIGHT PATH

In this month's *BJGP* there is a useful decision making guide by Martin.⁸ This is welcome: any help in this particular minefield is appreciated. Martin reminds us that such decisions must be based on patient-centred values, therefore by implication, not driven by political initiatives. Values cannot be derived from facts, but values need facts to work on. A precise understanding of the patient's medical and social situation is needed. But we also need to know the patient's preferences. It may be difficult or impossible to gauge current preferences so previous views and values should be sought. The views of the family will be important but must not override either the views or the best interest of the patient themselves. And the coping ability of the care home will provide a reality check. Our goal must be to maximise flourishing rather than to follow narrow biomedical pathways.⁹

It is better if such decisions can be anticipated. This gives us two advantages. Firstly we can discuss likely scenarios with patients or with family if the patient lacks capacity. If the patient has made a lasting power of attorney (LPA) for health and welfare then the attorney will have a duty to be involved, and the doctor will normally

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have a duty to respect their judgement. Secondly, however, advance discussion gives the doctor a chance to agree decisions with care home management and senior staff, if possible including nursing colleagues, as to what can reasonably be provided in the home. This may take pressure off less qualified front-line care home staff, especially if they feel poorly supported out of hours.

WHEN THE GOING GETS TOUGH ...

So far so good. But what when things do not go well? Some families have unrealistic expectations of the benefits of biomedical escalation at the end of life. Some families are at war with one another, with the home, or with us. Families may feel ill prepared to make such decisions and hold to life at any cost from inexperience, from fear, or from guilt. The multiple swords of Damocles from the risk of complaint, from the GMC, from lawyers, and from the CQC now hang over us all if things do not go smoothly.

And how often can we be certain of the patient's best interest in such unclear situations? Beauchamp and Childress remind us that:

*'... we see disunity, conflict, and moral ambiguity as pervasive aspects of the moral life. Untidiness, complexity, and conflict are unfortunate features of communal living.'*¹⁰

What is right may be unclear and will often be disputed. We may be unsure whether we possess the wisdom or the courage to achieve the patient's best interest. Thomas and McCullough (after Jameton) discuss the helpful concept of 'moral distress' when:

*'... one knows the right thing to do, but institutional constraints make it nearly impossible to pursue the right course of action.'*¹¹

We need to have ways of handling this with appropriate support from our colleagues.

So how do we imitate *Kelly's Heroes* and navigate through this particular minefield

without further casualties to our patients, our colleagues, and ourselves? If only we had a map! Martin's very practical article offers us a way forward.

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