Blog of the Month

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Advance Care Planning, A Culture Shift?

Dr Rebecca Marlor, a Geriatrics Registrar, reflects on the impact of COVID-19 on advance care planning:

Working as a geriatric's registrar in a district general hospital during COVID 19, it almost feels like there has been a shift of culture. I suspect, finally, we are all doing more advance care planning.

'Advance care planning is a discussion between a person, their family, carers and medical professionals about their future wishes and priorities for care.' This can include resuscitation status, escalation status (would we take this person to the intensive care unit or high dependency unit?), preferred place of death, advance decisions to refuse treatment and lasting power of attorney.

As a geriatrician, I often ask my patients what is important to them and what they would want to happen if they were becoming more unwell. Often, they are grateful for this opportunity to share their thoughts and plans. Patients often surprise me. Sometimes they don't quite understand and say, 'Well I have my will all sorted out!' or 'I've already paid for my funeral!' However, when you explain, they really can be quite profound 'I want to spend more time with my family', 'I don't want to live in a care home', 'I don't want to be dependent on my family', 'I just want to die peacefully'. Recently a patient even shared with me which specific care home they would like to die in. I feel so privileged to have these discussions and patients often thank me for them.

Now, the uncertainty around COVID 19 has pushed us all to advance care plan more often. Families are talking more to their relatives about their wishes. Doctors are making more escalation decisions and resuscitation decisions and taking an opportunity to discuss this with their patients. Although some may disagree, I think it is a good thing that we are talking to our patients more about what should happen if they become less well. After all, we all want to die well.

This got me thinking. How many people do we encounter day to day who are coming towards the end of their life? Who are these patients? How many of these do we talk to about their wishes for their future health? How many missed opportunities are there?

A colleague signposted me towards the Gold Standard Framework. This can be used to identify people who might be coming towards the end of their life and reflects those who might benefit from starting to develop their own personal advance care plan. Some of the criteria were surprising, some of them less so!

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Typically, we think of patients who have stopped treatment for cancer or other conditions. Or maybe patients with certain characteristics like developing frequent aspiration pneumonias. The Gold Standard Framework, asks us to think 'Would I be surprised if this patient dies in the next year? - also known as the 'surprise question'. There were also much more 'benign' indicators associated with specific diseases: UTI's in patients with dementia; weight loss, slowing gait and exhaustion in the frail elderly; more than 6 courses of steroids in 6 months in patients with COPD, psychological symptoms in those with treated heart failure and renal failure. These really are patients we meet every day in a hospital setting.

I suppose my take home message is that in our jobs we are all meeting patients who are coming towards the end of their life. We need to take more opportunities to open the dialogue before that 'crisis' point in the resuscitation room, or worst of all when they are peri-arrest. Of all the changes that COVID 19 has brought, I hope that this one will stick. I hope we will get even better at talking to patients about the end of their life and broaden the scope of our discussions. I don't think we should be intimidated but should feel privileged that we can ultimately talk to someone about one of the most important times of their life. They might even thank us…

References:

The GSF Prognostic Indicator Guidance (2011)

6.01 Advance Care Planning - MDTea Podcast (Aug 2018)