

# Life-limiting illness

## Breaking the news

**CATHERINE MASON** MB BS, MPH, FRANZCP

**GREG DE MOORE** MB BS, BSc(Med), FRANZCP, PhD

**There is no formula for telling a patient that all active treatments for their life-limiting condition have been exhausted, but preparation is indispensable. A considered, respectful and reflective approach will help patients and increase doctors' skill at showing care in such difficult conversations.**

*I was a fourth-year medical student when I first saw a patient given the diagnosis of terminal cancer. It was an outpatient clinic; surgery, our first term. The hospital was large, a teaching hospital, and the mood was often one of superiority.*

*The clinic was cold; the floor laid with linoleum. We – eight medical students dressed in small white coats – followed the surgeon from bed to bed. We shuffled to the first bed: the patient had been 'prepared' by the nursing staff beforehand. He lay on his left side wearing nothing but a white hospital gown, gaping at the back. He was alone. He was about 70 years old as I remember. We pulled a curtain around.*

*The surgeon came in and told us that the presenting symptom was 'PR bleeding'. Not once did he look the patient in the eyes. Not once did he ask the patient's name. The fear in the old man's eyes looking into his pillow has never left me.*

*Without further ado, the surgeon donned a glove and lubricated his index finger. No one said a thing. With finger still inserted the surgeon turned to us and announced that this man had a rectal carcinoma. The surgeon removed his gloved finger, walked out of the cubicle; we followed like a line of ducklings. The patient remained with knees raised, head down, naked to the world. We never went back to see him.*

Greg de Moore

**Medicine**Today 2019; 20(6): 55-57

Dr Mason is a Senior Staff Specialist Psychiatrist at Crown Princess Mary Cancer Centre, Westmead, and Nepean Cancer Centre, Penrith, Sydney. Associate Professor de Moore is Conjoint Associate Professor in Psychiatry at the University of Western Sydney; and Clinical Senior Lecturer at the University of Sydney Westmead and Blacktown Hospitals, Sydney, NSW.



**T**he most common causes of death in Australian adults over 45 years of age are cancer, vascular disease, dementing illnesses and chronic obstructive lung disease. These are, for the most part, chronic diseases with a variable course from diagnosis, but for most patients there will come a time when all active treatments are exhausted and the doctor's role is to provide supportive care until death.

Although palliative care physicians and nursing specialists have expert knowledge in this area of medicine, palliative care services cannot deliver all the necessary care to all patients in the end-of-life phase of their illness. Therefore, most doctors – especially GPs – will be part of their patients' end-of-life care. The GP is the foundation of the patient's professional care. His or her role in the care of the patient with the life-limiting condition is often the most important and decisive.

In this article we discuss only one aspect of this process: how doctors might convey news about a life-limiting illness to a patient. This is often the first in a series of conversations, as information may need to be revisited and goals reviewed, and it can take time to psychologically process the transition to the palliative phase of care.

### Breaking bad news

Patients live their lives in their own way; so do doctors. It therefore comes as no surprise that a patient will react in his or her own unique way when told about a life-limiting illness. There is no formula for how to impart such news to a patient. But there are patterns of good behaviour and clinical wisdom for the informing doctor on how to support, nurture and guide patients at this moment.

If at all possible, the patient should have with them someone they perceive as a support – partner, adult child, sibling, good friend – when they are seen in this context. That person will not only provide immediate support but is also likely to recall more of the content of the conversation, and may ask some important questions or raise very relevant concerns.

### Preparation

It is important that the doctor be organised and know the patient's history and investigation results before seeing them. In a long

day of office consultations it is impossible to stay attuned at every moment; however, at the point of imparting news about a life-limiting illness a high level of engagement and sensitivity is crucial. If the doctor is not highly attuned, the patient certainly will be. A doctor entering a consultation room flipping through notes as if just discovering what the latest test results showed will, apart from being rude, convey (correctly) that they do not know what is going on, and, even if they do know, that they care little.

### Setting the stage

A quiet consulting room is needed and phone calls should not be allowed to disturb the consultation. The doctor should look at the patient and give them full attention while speaking with them, which includes not looking at a mobile phone, not texting and not writing notes or sitting sideways with one eye on a computer screen. Standing or walking about, fidgeting or being distracted should be avoided. Although all of this may seem trite, in an age of intrusive smartphones and computer screens it is a rare patient who will forgive a doctor for such distractions. The basics of human interaction, so often casually neglected in current society, cannot be neglected in this setting. The doctor's manner might be the main memory the patient takes out of the room.

### The patient's understanding of the consultation

Before discussing any findings and the prognosis, the doctor needs to gain a sense of the patient's awareness of where their illness is up to. For example, do they understand why that blood test was done last week? Do they understand what was being looked for in that last CT scan? This will avoid assumptions and provide a clearer sense of how prepared the patient is to receive news, and will allow the doctor to shape the discussion. Although the details may seem simple to the doctor, the patient may have a wildly different perspective. They may have spoken to people outside

of medicine who have misguidedly either reassured or frightened them.

### What to say and how to say it

It can be helpful to gently ask the patient how much information she or he would like to go over. Although most patients want to know most, perhaps all, of the details about diagnosis and prognosis, not everyone feels this way. The doctor might want to gain a sense of how far the patient wishes to travel with this, at least in the first meeting. This approach also allows the patient to contribute to how the discussion unfolds.

In most circumstances, patients will be overwhelmed by reams of detail and will not take it in. Most patients want to understand the diagnosis, why the doctor judges this to be the end-of-life phase of the illness and what that actually means – how does the illness progress from here? Yet to avoid overloading the patient, the doctor needs to give factual information slowly and check for the patient's understanding of what they are saying.

The truth is that both the doctor and the patient struggle through this process. It is rarely the case that doctors feel fully confident; generally, they probe forward, sensing what needs to be said and what can be understood, while trying to be true to the diagnosis and likely outcomes. Few doctors ever become comfortable with this conversation.

The type of language used is important. Technical language should be avoided if possible; but even this depends on the patient, as some patients are well-versed and want to understand the situation in medical terminology. The doctor needs simply to be aware of the language they use and why they are using it.

Patients and their carers do not recall much of 'bad news' consultations and may need to go over information several times, absorbing a little at a time. Even in the most well-meaning of situations words can remain unheard, for example:

*Doctor: Well, looking at the scan from last week, there has been some progress. You*

*can also see these new spots over here ...*

*Patient (thinks): Progress! That sounds good. At least he's not seeing any more cancer.*

Talking about the prognosis is often the most challenging part of the consultation, and the doctor should first check with the patient whether they want to discuss this. Prognosis is an exercise in probability, and for some conditions there is little evidence so the prognosis relies more on clinical experience than hard science. Explaining this to a patient and carer can be challenging. Most doctors working with patients with life-limiting illness talk in terms of 'days to weeks' or 'weeks to months', avoiding numbers altogether, as numbers can take on the status of fact despite being only educated guesses.

### The importance of being 'with' the patient

Being aware of, and sensitive to, the patient's emotional state during this time is crucial. Empathy can be verbal, or it can be physical. It might be the doctor's physical presence, or perhaps a gentle touch on the forearm if it seems right. Everyone is different, and the doctor has to sense the moment for these exchanges.

Sometimes not much needs to be said – the task is to remain in the moment with the patient. Understanding a person's distress with a nod or a reflective statement may be what is needed. That a person feels understood is worth more than just about anything else at this moment.

The pitfall, of course, is the doctor going full-steam ahead with facts because of their own anxiety. It may be that doctors fear silences in a consultation, or not knowing what to say. Perhaps an overwhelming reaction from the patient or their family is feared. Being able to withstand the temptation of excessive talking, but rather to gently reflect and be guided by the patient, can be more therapeutic. Patients may recall the tone of the moment or the look given far more than specific words.

## Planning

Patients may interpret the outcome of the bad news consultation as 'there's nothing more we can do for you'. However, experts in palliative care advise it is more meaningful, more helpful, and more accurate to frame the discussion as a change in the goals of care. Comfort and preservation of function become the priorities. Forming an immediate plan may give back at least some small sense of control to the patient and their family. Giving everyone something to do, to plan for, will reduce uncertainty. Most importantly, the doctor needs to communicate their commitment to the patient throughout this next phase of care, letting them know they will not be 'abandoned'.

Patients will often be thinking about how to tell others, especially close family, about the news. They may have concerns about how to talk to young children within the family, how much to share and how to phrase it. They may have concerns about what to share on social media as well as how to respond to others' comments and (well-intentioned) messages. Doctors could consider providing take-home information in multiple media formats (printed resources, links to podcasts, video) and try to find material appropriate to the literacy, health literacy and cultural background of patients and carers.

## Afterwards

At the end of the consultation it might be helpful for the patient and their carer to be allowed some quiet time in private to help compose themselves before leaving the office.

## Learning how to break bad news

Breaking bad news is a skill that can be learnt (some resources are listed in the Box). Although all doctors have differing levels of innate ability in this regard, all can improve. Students learn by watching others, by doing, and by making errors. There is no guaranteed pathway, yet if time is spent reflecting on each conversation, doctors will learn from experience what works for them and what feels unnatural.

## RESOURCES

### Books

Back A, Arnold R, Tulsy J. Mastering communication with seriously ill patients: balancing honesty with empathy and hope. Cambridge, NY: Cambridge University Press; 2009. ISBN:978-0-521-70618-6

Chochinov HM. Dignity therapy: final words for final days. Oxford: Oxford University Press; 2012. ISBN: 978-0-19-517621-6

### Journal articles

Baile WF, Buckman R, Lenzi R, Glober G, Beale EA, Kudelka AP. SPIKES – a six step protocol for delivering bad news: application to the patient with cancer. *Oncologist* 2000; 5: 302-311

Clayton JM, Hancock KM, Butow PN, Tattersall MHN, Currow DC. Clinical practice guidelines for communicating prognosis and end-of-life issues with adults in the advanced stages of a life-limiting illness, and their caregivers. *Med J Aust* 2007; 186(12 Suppl): S77

### Online resources

Advance Care Planning Australia website: [www.advancecareplanning.org.au](http://www.advancecareplanning.org.au)

Cancer Australia. Clinical guidelines for responding to suffering in adults with cancer. Available online at: <https://canceraustralia.gov.au/publications-and-resources/clinical-practice-guidelines/clinical-guidance-responding-suffering-adults-cancer> (accessed June 2019)

Cancer Australia. Finding the words: starting a conversation when your cancer has progressed. Available online at: <https://canceraustralia.gov.au/publications-and-resources/cancer-australia-publications/finding-words-starting-conversation-when-your-cancer-has-progressed-0> (accessed June 2019). *This is a guide to initiating discussion about the spread of cancer, which could be a framework for other conditions*

NSW Health. Making an advance care directive. Sydney: NSW Health, 2017. Available online at: [www.health.nsw.gov.au/patients/acp/Pages/acd-form-info-book.aspx](http://www.health.nsw.gov.au/patients/acp/Pages/acd-form-info-book.aspx) (accessed June 2019)

### Training in communication skills

Medical indemnity organisations and some medical colleges sponsor face-to-face training in communication skills – college websites and indemnity organisation websites can be checked for current offerings

## Conclusion

What is certain is that a patient and family will recall the doctor's words, actions and inactions long after the doctor has forgotten most of the conversation. They will be highly sensitive to how the news is delivered and, rightly or wrongly, praise or condemn the doctor for their manner as much as anything they might say. At times doctors may feel this challenge is beyond them, and sometimes we get it wrong. But for the most part, with a focus on planning, attention to detail and a caring manner, it can be done well.

MI

*I am a senior consultant working in a cancer service. My clinics are in the same space as my oncology and haematology*

*colleagues, and I see their patients on their wards. From time to time they need to talk with patients and their families about disease progression and transition to end-of-life care. They are thoughtful, respectful and considered in the way they do this, and often take a pause before and after, to reflect, sometimes with other members of the team. We've come a long way since my medical student days, and while I'm sure there is still room for improvement, many of us who witnessed encounters like the one at the start of this article decided early on to do it differently and learn to do it better.*

Catherine Mason

COMPETING INTERESTS: None.