



## PRACTICE

## WHAT YOUR PATIENT IS THINKING

## Remembering the person

Meetings between health professionals and patients with cognitive decline and their carers can be challenging, but this author describes how some encounters can be positive even if the news isn't good

Anonymous

There isn't a good part to watching someone you love struggling with a progressive neurological condition that includes dementia. The insidious but steady decline in cognitive and motor functions leads in only one direction. It seems such a cruel reversal of childhood: instead of learning to walk and talk, he is forgetting how to. And when a urinary tract infection led to a prolonged hospital stay and a considerable deterioration in condition, the outlook was wholly gloomy. A steep cognitive decline, complete lack of continence, no more standing, not much solid food, and supervision required at almost all times.

## An impersonal list of dos and don'ts

A definite low point was when we, the family, were summoned to a "family meeting" at the hospital. We found ourselves listening to an assembled group of therapists—a physiotherapist, a speech and language therapist, and an occupational therapist—describing to a close family the latest losses of function and how to manage them. We listened to a seemingly endless list of "he can't do this and you need to prevent him from doing that and watch out for development of the next deterioration" that seemed so relentless and depersonalised that even the patient's endlessly tolerant primary carer lost her cool. "We have been looking after him at home for the last 10 years of decline, you know." All of this was accompanied by the financial anxiety that comes from being told that his care needs—which include being fed, reminded to drink, hoisted out of bed by two people, and turned to avoid bed sores—are social, rather than health needs, and so need to be self funded.

## Kinder, practical, and focused advice

What a surprise it was to find that a trip to the neurology clinic a few days later actually brought some sunshine and heart's-ease. Not that there was any good news: there wasn't, but the example of caring and compassion was such a balm and in stark contrast to those brash young therapists. What did the neurologist get so right? It wasn't just that she was kind—she was kind but also practical in her advice, and focused entirely on the people in front of her.

## Participation for all

The neurologist managed to give each of the people in the room (including a medical student) her full attention but not to the

exclusion of any of the others. She performed the necessary tests of cognition with sensitivity. When the patient's hands had difficulty mimicking her pinching motion, she listened with interest and sympathy to his wife describing how much practical and artistic work those hands used to be able to do. And when she was having a conversation about the patient and his needs she apologised to him for seeming to talk across him. She didn't seem to lose sight of the man he used to be, despite his lack of participation in events.

## Knowledge and care for the carers

And when the patient had left the room she answered difficult questions simply and fully: what can we expect to happen next, and on what time frame? How long might this go on? Most importantly, we felt listened to and cared for ourselves. We left the consultation clear about the prognosis and current and future needs, and somehow stronger in our ability to provide for them. And I felt glad that a medical student was learning the art and science of a family consultation from such an expert in providing caring attention to both patient and carers.

## What you need to know

- Giving information clearly and in detail can be done even better when combined with sympathy
- Remember to treat the patient as someone who is in the room, even if cognitively he or she is not entirely present
- Caring for the carers helps the patient too

## Education into practice

- Some of the information on progression felt relentless and depersonalised. When the decline of cognitive and motor ability is all in one direction, how can you better share information in a way that supports patients and carers?
- The more successful consultation included, and excluded, the patient at times. Are there better ways to balance involvement of carers and patients, particularly when caring for those with short life expectancy?
- Information to keep a patient safe might restrict activity and sound like a list of "do's and don'ts." Can you think of better ways to offer advice on activities that involve more risk?

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