

debates and issues

Dementia diagnosis and white lies: a necessary evil for carers of dementia patients?

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I am the daughter and one of the main carers for my 90-year-old mother. My mother was diagnosed with dementia in 2015. In this article, I reflect on dealing with my mother's progressive disability, with a focus on one experience. I explain why I believe withholding the truth is sometimes an acceptable, or even a preferable, course of action. The article illustrates how differing advice and lack of guidance about dementia diagnosis and 'truth-telling' play out in practice.

key words dementia • Alzheimer's disease • ethics of care • diagnosis

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My story

'Where's Dad?'

My mother is lying in a hospital bed. She looks pale and thin, her skin hangs off her bones like a translucent sheet. A tube, I assume a drip, rehydrating her, is attached to her wrist. Her body is hunched and emaciated, but she leans forwards eagerly and clutches my arm.

'Where's Dad?'

It is March 2016. I gaze out of the window, racking my brain for an answer. Her bed is located in a top-floor ward of the John Radcliffe Hospital in Oxford. The view is great – dreaming spires aplenty.

'Look at the view', I mutter, *'It's beautiful isn't it?'* Distraction tactics. Hopefully, the topic will be dropped. However, my mother is insistent.

'Where's Dad? Is he coming soon?'

Time stands still for mum, I think. Sometimes, she lives in the present, but at others, she is operating in the past. Some time before the onset of her dementia – 2012 maybe? Or even earlier? Locked in the time when, I reason, she stopped laying down memories about new life events. On this occasion, Mum has been admitted for a urinary tract infection, which exacerbates her confusion and memory problems.

Mum's dementia diagnosis is recent and no attempt was made to explain the 'stage' of her condition. Mum was not informed of her diagnosis, which was 'mixed vascular dementia and Alzheimer's disease'. The diagnosis itself arrived in an email, cc'd to myself and my sister. The phrase used in Mum's presence was 'memory issues'. I supposed the memory clinic staff were leaving it to us to discuss the diagnosis with Mum. Although there seems to be a plethora of literature on the biological causes of dementia and Alzheimer's, risk factors, and how important it is to diagnose early, much less is written about how families should communicate the diagnosis to their relative. There are also conflicting messages in the ethics literature about when, and how, to tell the truth. Twenty years ago, a survey showed that psychiatrists rarely informed their patients about a dementia diagnosis and almost never discussed prognosis (Rice and Warner, 1994), but more recent work suggests that things may have changed (Dooley et al, 2015). When asked if they would want to be informed of a dementia diagnosis, 92% of attendees at primary care practices in the late 1980s said that they would (Erde et al, 1988) and most older patients in a more recent UK survey felt the same (Marzanski, 2000). It seems that people want to know the worst.

Guidance promotes early and accurate diagnosis (Carpenter et al, 2008), although few published studies have explored the advantages and/or risks of this (Dubois et al, 2016). The National Health Service in the UK emphasises the importance of early identification. The received wisdom is that being diagnosed early can help patients get the right treatments and find the best sources of support, as well as make decisions about the future (Bunn et al, 2012). Like other diagnoses, a dementia diagnosis can provide a useful explanation for unusual behaviour and experiences (Russell and Norwich, 2012). I pondered the benefits of telling Mum about her dementia. Could the knowledge that she has a diagnosis of an incurable degenerative condition adversely affect her, especially when the prognosis is basically 'you are going to get sicker and sicker and then die'? Would it make her hopeless? Would it lead to her giving up attempting to live a semi-independent life? Might her mind deteriorate faster as a consequence? According to research, the confirmation of a diagnosis is associated with depression and loss of role in some people (Liffé and Manthorpe, 2004; Milne, 2010). In fact, mindful of the survey evidence noted earlier, I did discuss the diagnosis briefly with mum. However, later the same night, she had forgotten about any diagnosis or having discussed it. She forgets how to open her fridge. She forgets how to turn on the TV. She forgets information discussed at the start of a phone conversation before it has ended.

'Where's Dad? Is he coming soon?'

I stare again at the dreaming spires and rack my brain for a solution.

Quite a few clinicians and academics have written strong opinion pieces debating the ethical and moral dilemmas about lying to patients with dementia. In the *Journal of Dementia Care*, German theologian Christian Müller-Hergl (2011) argued that lying to someone always compromises a relationship, and others suggest that lying in any way or form to a person living with dementia is considered unethical and damaging to the person's right to autonomy and trust (Kitwood and Bredin, 1992). Philosophers such as Bakhurst (1992), writing in *Journal of Medical Ethics*, starts from the position that lying (by a clinician) is wrong but that exceptional circumstances may justify it.

Culley and colleagues (2013) note that there is currently no official guidance in the UK suggesting that 'lying' or 'not telling the truth' to any people living with

more severe dementia is advisable. Several attempts have been made to try to develop guidelines for carers of people with dementia (James et al, 2006). Some note the difficulty in defining what constitutes ‘a lie’ and the moral complexities of what lies can be told, by whom and when. An underpinning principle is that whatever they are told must be judged to be in ‘the best interest of the patient’. Some authors suggest that, once deployed, lies should be used consistently by carers and in care settings. I find this prospect alarming. For the patient, this is a scenario in which everyone knows that the lie you have been told is a lie except for you; the so-called ‘special method’ encourages this approach (James, 2008). It seems a potentially frightening world for the patient, where relatives conspire with each other and with nurses, doctors and family friends to keep you in the dark – away from the truth, weaving an elaborate web of lies fit for a sci-fi movie. The Matrix springs to mind. No wonder dementia patients get paranoid.

‘Where’s Dad? Is he coming soon?’

It is 2016 and I think about the sources that suggest you should always tell the truth; you should never lie. You should not knowingly deceive the person with dementia. I draw a deep breath.

‘Dad’s dead, Mum.’

‘What?’

Mum looks incredulous, shocked, as though I had physically assaulted her. I guess in some way I had.

‘Dad’s dead’.

‘When did this happen?’

‘About two years ago, now, Mum.’

‘But why, why didn’t I know that, why wasn’t I told?’

Tears are spilling down her cheeks now. Her distress is palpable.

‘You were told, Mum. You were with him when he died.’

‘I don’t remember that. How did he die?’

‘You were there, Mum. You were with him when he died. It was here. In this hospital.’

‘I don’t remember that.’

And so the painful conversation proceeds. Question after question.

‘What about his funeral? Why wasn’t I invited?’

‘You were there, Mum.’

‘Who else knows about this? Does your sister know?’

‘She was there too, Mum.’

And so on and so on.

It is one of the most upsetting experiences I have ever had, and I hardly dare imagine what it means to Mum. To be told the news that her partner of 50 years is dead is completely overwhelming to her. The dual news that she has forgotten this information is almost certainly both frightening *and* disturbing. Is it any wonder that she frequently becomes distrustful, fearful and suspicious? How would you react if a close family member – your daughter – told you that your partner was dead, had been dead for years and you had simply forgotten? Would it not be more likely that

the person was lying, deliberately trying to mislead you? It would be hard for anyone to make sense of that, but sense must be made of it, and only two explanations are possible. Either you are deluded or, for some reason, that person – your daughter – is lying. No wonder fear and suspicion are common symptoms of dementia. Not so much symptoms, I think, as understandable reactions.

In this case, at this time, March 2016, my mother accepts the loss of my father and the news devastates her. Many hours later, in the lift going down from the ward, I decide that I will never, ever, put my mother through that again. In some scenarios, ‘the truth as you know it to be’ is simply too painful and results in too much distress, too much anguish. There is too much at stake to make it a tenable option.

As a person who supports a family member with dementia, I cannot now agree with those who argue that honesty is always the best policy. Ethical issues are sometimes, for me, a most challenging matter. Unlike issues for professionals, they arise from a personal context and are shaped by my long-term relationship with my mother and sister (Hughes et al, 2002). The tricky topics of Mum’s future care, managing her finances and how much to involve her in decision-making crop up on a daily basis.

I believe that the decision regarding honesty needs to be pragmatic and in the patient’s best interests. That decision should be at the discretion of the carer. In reality, thousands of carers across the country (disproportionately women, to whom this low-status, low-pay, role is often allocated) follow their gut instinct on this; that pragmatic approach is the one I intend to adopt in future. However, it is a very grey area. I wonder about a slippery slope of lies too, as I know my mother is vulnerable to manipulation and exploitation. My mother has accumulated wealth. The vast majority of professional carers for people with dementia are low-paid women. Most do their absolute best, but sometimes, when wages are low and staff are poorly qualified and/or motivated, they may struggle with their own financial difficulties.

April 2017. I see my mother lying on a hospital bed. I now see white lies as part of the solution to making her life with her condition easier, not part of the problem. The view from the top floor of the John Radcliffe Hospital is as good as ever.

‘Where’s Dad?’

‘He’s not here right now’ – I smile at her and she smiles serenely back.

I have become adept at the art of partial information – of the white lie (eg ‘Dad is not here at the moment’ used as a sort of euphemism instead of ‘Dad has passed away’).

As I write, it is 2018. White lies have become a necessary evil to me, a tool to be utilised when required to help Mum navigate the complex world that her disability allows her to experience. Sometimes, the truth is not so beautiful after all.

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