

17

Diagnosis

Introduction

The first area I shall discuss centres on ethical issues in connection with the diagnosis of dementia.

Vignette: Freda Smith's reluctance to be diagnosed

Mrs. Smith, a widow who lived on her own, had shown signs of increasing cognitive impairment for some while. Her daughter was very worried about her. The GP visited her at home (she would not attend the surgery and had become annoyed when her daughter tried to make an appointment for her) and tried to persuade her to accept a referral to the local memory clinic. She refused, saying there was nothing wrong with her, that it was just her age, but that she was coping perfectly. The GP did notice some deficits in terms of her recall and orientation but felt it best not to push matters. Six months later, one cold night she locked herself out of her house and her daughter was worried sick. The GP made a referral to the local old age psychiatry team asking for an assessment at home.

When the team (a psychiatrist and nurse) visited and revealed who they were, Freda became extremely annoyed. She denied any problems and gave semi-plausible excuses for the various things that had happened. She told them they were not to discuss her personal business with her daughter, whom she claimed was just after her house. When the psychiatrist gently tried to suggest that there were now some noticeable difficulties with some aspects of her memory, Freda screamed at him to get out of her house and said she was not interested in hearing anything about her memory, which was, as far as she was concerned, good enough. She said it was her right to live as she chose. The doctor and nurse left, but the nurse visited again a week later having promised the daughter to do so. Freda was then more placid, but the moment the nurse started to say anything about memory, or forgetfulness, or difficulties around the home, she started to become irate and agitated. If they spoke about non-threatening issues, she was calm and pleasant and was happy for the nurse to help her with a few tasks, such as throwing away some food items from the fridge which had started to rot.

Ethical issues in connection with diagnosis

Freda is an extreme case in that she decidedly does not wish to have a diagnosis, but she was not exceptional at the turn of the century when

Marzanski (2000) found that 9 out of 30 participants did not wish to know what was wrong with them or receive any information. These days, many people do wish to know what is wrong with them when they sense there is something amiss. But it is not uncommon to find people who are ambivalent about receiving a diagnosis or who, because they do not recognize any problems, do not quite understand why they are being seen by a doctor or other professional. Perhaps an initial place to start our discussion of Freda and of the ethical issues around diagnostic disclosure is to recognize that it is not totally irrational to wish to avoid a diagnosis. The almost globally accepted professional or official mantra is that early diagnosis is a good thing, but it is not clear this is always the experience of those who actually live with a diagnosis.

We have already discussed stigma (Chapter 7). In Chapter 14, we discussed the use of biomarkers to make earlier diagnoses and the possibility of making a prodromal diagnosis of non-dementia Alzheimer's disease (that is, where there is evidence of Alzheimer's pathology but an absence of illness). We also have to recognize that the absence of curative treatment, and the marginal utility of the current relatively few medications, undermines to some extent the value of a diagnosis. All that can be said is that post-diagnostic support might be valuable. But someone as feisty as Freda might question what this actually entails. She may or may not welcome the suggestion that she could make a Lasting Power of Attorney (LPA) or, if she were lucky, join a group to discuss the diagnosis she does not wish to receive.

To say that the mantra in favour of early diagnosis is the conscious or subconscious result of a cabal of researchers (who seek funding for the next research project), drug companies (who wish to make profits) and governments (intent on keeping the pharmaceutical industry based in their countries), inevitably sounds like mere conspiracy theory. But to raise questions about the drive for early diagnoses is certainly not unethical (Le Couteur et al. 2013). It may be that generally, at a public health level, it is a good thing to diagnose people earlier, but at the individual level the person's wishes and values should be heard without the pressure of the public health message. As so often, it is the nuance of individual cases that is crucial, even if on the whole an earlier diagnosis is better than a later one.

It also throws into light the accepted but controversial diagnosis of mild cognitive impairment (MCI), mentioned in Chapter 1. Lohmeyer et al. (2021) showed a good deal of uncertainty amongst those diagnosed with MCI. The participants were uncertain about the meaning of 'MCI' and about the validity of specific biomarkers. This reflects concerns and uncertainties about the concept of MCI highlighted some years ago: about how the label might affect the person's sense of self (Corner and Bond 2006), about the status of the concept itself (Graham and Ritchie 2006) and its clinical standing (Gaines and Whitehouse 2006). It is a diagnosis, which in practice is loosely defined, but not a disease, and in itself carries no certainty for the individual – not even the certainty of future dementia. It is true that 'MCI' has become accepted parlance, part of normal practice, and that the 5th edition of the American *Diagnostic and Statistical Manual* (DSM-5) has embraced it under the rubric

of 'mild neurocognitive disorder', but the conceptual problems with the terminology persist.

Freda, who does not wish to hear the word 'dementia', might be impressed by the thought that we should get rid of it. Hachinski (2008) declared that 'The concept of dementia is obsolete. It combines categorical misclassification with etiologic imprecision' (p. 2172). Meanwhile, Trachtenberg and Trojanowski (2008) argued that 'dementia' was a word to be forgotten. It is unkind and 'can easily rob patients of their humanity in the eyes of others and, more important, in their own eyes'. They continued: 'At its unkindest, it is a word without hope, which is a crucial tool when faced with a devastating illness' (p. 593).

I have also advocated that 'dementia' should be replaced by some other words (Hughes 2011b: 12–19). This is partly because it is simply insulting to tell someone they are out of their minds, which is what the etymology suggests. So 'dementia' encourages stigma. But it is also, as Hachinski (2008) suggested, diagnostically imprecise. Hearing that someone has dementia does not tell you what is going on. They may have movement problems, difficulties with speech, behavioural disinhibition or whatever.

In place of 'dementia' I commended (Hughes 2011b: 16–19) a descriptive syndromal diagnosis: acquired diffuse neurocognitive dysfunction (ADND). I argued this was no more complicated to understand than attention deficit hyperactivity disorder (ADHD) and serves to explain what is going on. The exact type of ADND could then be specified as Lewy body disease, vascular disease and so on. Some were critical of my suggestion, but DSM-5 no longer refers to 'dementia' and instead uses the label 'major neurocognitive disorder' (American Psychiatric Association 2013). The point is that the word 'dementia' can be regarded as otiose. There are ethical reasons to discard it. Indeed, some go further and say that even the more specific label of 'Alzheimer's disease' should also be discarded; in its place we should talk of brain ageing, which occurs in different ways in us all (Whitehouse and George 2008).

Turning to the question of diagnostic disclosure, until the end of the 20th century the tendency was to be paternalistic; this became gradually less so in the 1990s (Rice and Warner 1994; Gilliard and Gwilliam 1996; Clafferty et al. 1998). Many practitioners felt it was not necessary or would be too upsetting to tell people they had dementia. By the end of that decade, in a research environment, carers expressed the view that patients and families can benefit from being told the diagnosis (Smith et al. 1998). The researchers noted that one carer had felt abandoned after diagnosis, emphasizing the need for post-diagnostic support; and they pointed to the ethical issues of autonomy, the right to know and confidentiality.

Even at the start of the decade, Drickamer and Lachs (1992) had posed the question: should patients with Alzheimer's disease be told their diagnosis? On the whole, they thought they should because of the need to maximize autonomy which requires that people are given the best available information (even if it is uncertain) and enabled to make advance decisions. They highlighted the fundamental requirement to be truthful. Nevertheless, they also recognized that the erosion of decision-making capacity in dementia might make things

difficult and that there had to be sensitivity to the possibility of the diagnosis causing harm, such as depression. Certainly Husband (2000) found worries that giving the diagnosis seemed likely to cause low self-esteem, self-stigmatization and impaired quality life, although the possibility of helpful interventions was also noted. The suggestions of Drickamer and Lachs (1992) about the ethics of diagnostic disclosure remain convincing.

The studies in the late 1990s and around the turn of the century almost certainly reflected the new pressure to be open with people because of the licensing of the cholinesterase inhibitor drugs and later of memantine. Valid consent to take the drugs required honest diagnostic disclosure. Pinner (2000) stated in an editorial: 'It is not a question of whether to tell the truth or not; we must be truthful to our patients. When and how are the questions that need to be explored, with the help, of course, of our patients' (p. 515).

At the start of the new century, there was still evidence that in many cases people were not being given the diagnosis, even if rates were improving, often because of concerns about the consequences for the person's mental health (Marzanski 2000; Jha et al. 2001; Pinner and Bouman 2002). A study in Finland seemed to show an improvement: 93 per cent of carers confirmed that a diagnosis had been given openly to the person living with dementia (Laakkonen et al. 2008). Nevertheless, 55 per cent of those with Alzheimer's disease had developed depressive symptoms. Recall that Schmutte et al. (2021) showed a 53 per cent increase, compared to the general adult population in the USA, in the suicide rate in the first year after diagnosis. Contrariwise, more than 10 years previously Purandare et al. (2009) found a relatively low prevalence of suicide in people with dementia in England and Wales and fewer psychiatric symptoms before death when compared to controls.

Many of those writing at this time were able to give ethical arguments to support their commentaries. Marzanski (2000) gave arguments in favour of truth-telling: respect for autonomy, the need for trust in the doctor-patient relationship and acknowledgement of reciprocal obligations, fidelity and promise-keeping. He also gave arguments for limited truth-telling or lying. First, the therapeutic privilege: 'Honesty should not be confused with cruel openness' (p. 112). So, if there is the threat of harm following disclosure, 'benevolent deception' might be justified. Secondly, there may not seem to be an ethical imperative to tell the truth if the person is unlikely to understand the information. Thirdly, some people simply do not wish to know their diagnoses. Marzanski's very sensible conclusion was that we should ask people if they wish to be given information about what might be wrong.

Pinner and Bouman (2002) found that older people generally wanted to be fully informed, but the views of people living with dementia were largely unknown – a point confirmed by Bamford et al.'s (2004) systematic review of the literature. Pinner and Bouman (2002) highlighted the place of the ethical principles of autonomy, beneficence and non-maleficence (see Chapter 3) in deciding whether or not to disclose the diagnosis. They also outlined their practice, which was (as suggested by Marzanski 2000) to ask people if they wished to know a diagnosis. Where the relatives did not wish the person living with

dementia to know the diagnosis, they commended a ‘patient-led’ discussion – involving the family and the person with the diagnosis. They wisely suggested that ‘disclosure must not be seen as a one-off event, but as an ongoing, dynamic process and a fundamental part of the care of a patient with dementia’ (p. 133).

On the basis of ethnographic research, Hillman (2017) agreed with this point: ‘Focusing on a distinct moment of diagnosis disclosure ... fails to recognise the negotiated nature of ethical decision-making that occurs over time and in collaboration..., and the ethical interest in broader contextual issues beyond the ‘moment’ of disclosure’ (p. 57).

The Nuffield Council’s report encouraged the idea of a ‘timely’ diagnosis (Nuffield Council 2009: §3.17, p. 43). This was suggested to the working party that produced the report by the Alzheimer’s Society (footnote 134 on p. 43). A ‘timely diagnosis’ can be defined ‘as when people with dementia and those around them are ready for and will benefit from it’ (Brayne and Kelly 2019: 124). In Brooker et al. (2014) a diagnosis is ‘timely’ when it can be used by people to ‘... make sense of what is happening to them, make lifestyle changes and plan for the future’ (p. 686). This was in the recommendations of the European Union’s ALCOVE project, which also set out four principles ‘to maximise benefit and to reduce harm associated with diagnosis at an earlier stage’ (Brooker et al. 2014: 682). They were:

- 1 Diagnosis should be available and accessible to all when changes in cognitive function are first noticed;
- 2 Fear and stigma need to be decreased in order to increase diagnosis;
- 3 The person’s rights and wishes about diagnosis should be centre stage;
- 4 Giving and receiving a diagnosis of dementia should be seen as part of an adjustment to living with dementia (pp. 686–687).

It is incontrovertible that when people are seeking help they should be diagnostically assessed. The worry, however, is that – despite the benefits of an early diagnosis – we are witnessing the medicalization of normal ageing. If we look for changes in cognitive function as we age, we shall find them. This does not mean that we require a diagnosis of dementia. When that diagnosis is required is an evaluative judgement which must be largely guided by the person concerned. The worry is that societal pressures will overrule individual judgement. The ethical point is that caution is required rather than blanket policies. Of course, blanket policies can produce benefits at a societal level which are not seen at a personal level.

Just to pick up one remaining thread from the story of Freda Smith: confidentiality. She does not wish her daughter to be involved in discussions about her health. During evidence-gathering for the Nuffield Council’s report (see Chapter 16), we heard that some family carers were upset when doctors would not involve them in decisions about the person they cared for because of the need to maintain confidentiality. The report suggested that ‘the appropriate attitude of professionals and care workers towards families should be that of partners in care, reflecting the solidarity being shown within the family’

(Nuffield Council on Bioethics 2009: §3.12, p. 41). Of course, if someone living with dementia has the appropriate capacity, then that person's refusal to share information must be respected. But if they lack capacity – for instance if they have no idea of the risks they have been taking or of the multiple times they have been ringing their relatives with the same request – and cannot understand why their families might need to be involved, then a decision can be made in the person's best interests and for the sake of their well-being, which may or may not involve sharing confidences, for example about the diagnosis. Elsewhere, we have suggested that, although confidentiality is an important principle, it 'is less important than the respect and trust implicit in the nexus of caring relationships that surround and aim to support the person with dementia' (Hughes and Louw 2002a: 150).

Patterns of practice and Freda Smith

Freda does not want a diagnosis and does not seemingly want help, although she is happy to see a friendly face. Thinking of patterns of practice leads to a focus on coherence. First, there is the need for internal intra-practice coherence. What does the practice of giving a diagnosis entail? Well, it needs to be done in a certain way. Practitioners need to understand the person's own understanding or expectations and 'warning shots' need to be given, rather than the bad news being blurted out. Whitehouse (2004) said: 'The conversation about diagnosis sets the stage for what will hopefully be a healing relationship between patient and clinician' (p. 124). Forcing the issue with Freda, therefore, will never do. Frisoni (2004) made the discerning comment that 'patients with anxiety-related behaviours do not ask for the diagnosis because they do not wish to know – vaguely and indistinctly they know already and their anxiety would increase intolerably if the verdict were made explicit' (p. 125). It is a question of starting where the person is and moving on to discover what the person can tolerate, a point recognized in the ALCOVE principles set out above (Brooker et al. 2014). Freda has made it obvious that she cannot tolerate the implications of an assessment. Post (2004) regarded compassionate disclosure of the diagnosis as 'a moral act of respect for patients', but he also went on to say it is 'an opportunity for human resilience and community, and a necessary practical step toward future planning' (p. 126). Respecting Freda implies keeping clear of the diagnosis: she does not wish to show resilience beyond what she is already showing.

Similar considerations are in play when it comes to intra-personal internal coherence. Many commentators have made something of the analogy with diagnoses of cancer. Some years ago, that diagnosis would have been avoided if possible; but not now. Breaking bad news in cancer care is a reasonable paradigm for dementia care (Maguire 1999). The question to ask is: what would I do in other circumstances? Employing compassionate and sensitive techniques, I would not seek to impose investigations or diagnoses on people. Of course, there might be extreme examples where compulsory care is inevitable. One can

imagine this eventually in Freda's case if things do not go well. For now, a casuistic path can be trod (see Chapter 5). Are there in fact differences between cancer and dementia? Some cancers are curable, dementia is not. Cancers can be regarded as extrinsic to the self, whereas dementia threatens something more intrinsic to the self perhaps. So, whilst, to be coherent, our practices might be more like cancer, the need to push a diagnosis might well be regarded as less of an imperative in dementia care.

But what about external coherence, where we wish to establish coherence between a person's patterns of practice and the moral norms that define and constitute the good life for human beings? That is, what virtues are required in this pattern of practice? The virtue of practical wisdom is frequently going to be relevant and may be seen in the notion of a 'timely diagnosis', discussed above.

But we need more than this. We also need compassion, honesty, bravery, genuine warmth and hope. The team need to engage with Freda Smith, as the nurse is now doing, in an unthreatening manner, to provide a sense of security, friendship and hope. This may also help her daughter to feel less stressed, which in turn may help their relationship. The aim is to allow Freda to continue to live an independent life for as long as possible. This is to respect her autonomy; but we also need to be cognisant of her dependence. The importance of the relationships established at this point cannot be over-emphasized (not least because the professionals need to confirm the good intentions of Freda's daughter). Being-with now will ease any doing-to in the future. But more than this, making the journey to a diagnosis, and possibly not to a diagnosis, in a low-key, harmonious, supportive and loving manner coheres with the intention of allowing Freda to live as good a life as she can, given the reality of the situation for her.

Conclusion

Getting diagnostic disclosure correct is a complex yet crucial task. Practitioners must attune to the individual dynamics of the person's situation. People have a right to know their diagnoses, but only if they wish to, which most will. How, when and where are the crucial questions, as well as by whom? Much will depend on the quality of the relationships that are or can be established and the trust and hope that such relationships engender (Merl et al. 2022). Giving the diagnosis is not detached from the rest of our practices. So our approach to the person to whom we can give a diagnosis of a particular form of dementia must sit within and square with our general approach to other people who are potentially vulnerable, anxious or threatened.