

# What should we tell people about dementia?

Gill Pinner & Walter Pierre Bouman

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**Abstract** This article reviews what we should tell patients and carers about dementia. The attitudes and views of patients, carers and peer groups are examined, as is the practice of doctors and other professionals working in dementia care. Factors influencing the decision to disclose the diagnosis of dementia, including the degree of certainty of the diagnosis, the degree of insight of the patient and the severity of the dementia are considered. Advantages, disadvantages and ethical issues of disclosure are discussed, as well as when or whether and how to disclose the diagnosis. Flexible guidelines regarding the process of disclosure are introduced.

Over the past decade, advances in the accuracy of the diagnosis of Alzheimer's disease, as well as progress in the genetics, aetiology, pathology and therapeutics of the condition, have stimulated a debate on whether patients should be informed of their diagnosis.

Prior to this, it was the culture within medicine for practitioners to withhold information from patients. This attitude was based on a widely held view that the truth may be damaging and that the disclosure of medical facts might destroy a patient's hope or motivation.

The patient's right to know is now a well-established priority, with patients demanding more equality within the doctor–patient relationship and wishing to be more actively involved (Department of Health, 1992). In the area of dementia care, professionals' practice is changing rapidly, partly driven by representational organisations such as the Alzheimer's Society. Education into the illness and public awareness have also improved, with public figures such as Ronald Reagan and Charlton Heston announcing their diagnosis and John Bailey's publication of a memoir of Iris Murdoch, with its subsequent cinema version.

## 'Truth-telling' and dementia

Until recently, there was a great sense of therapeutic nihilism in the area of dementia care and practitioners often attempted to protect their patients

from the harsh reality of such a diagnosis. When giving a diagnosis of dementia, not only is there the factor of it being a progressive terminal untreatable illness, but also this particular illness is changing and reducing the patient's cognition – their ability to remember, their ability to make judgements, to have insight into their situation. This has encouraged the practice of using the patient's relatives and carers as a proxy when considering discussion of the diagnosis, treatment and prognosis of the illness, without necessarily having the patient's consent (Barnes, 1997).

Compared with the progressive changes made towards disclosure of diagnosis in cancer, attitudes towards diagnosis in dementia are still some way behind. It is doubtful whether openness in relaying a diagnosis to patients has been achieved as common practice, although relatives and carers are more likely to be told the truth (Brodaty *et al*, 1990; Rice & Warner, 1994). However, without clear, shared communication to both patients and carers together, this may cause difficulties within families, members being unable to confide and share distress, and harbouring guilt and shame.

With the introduction of new anti-dementia drugs, akin to the advances in chemotherapy, radiotherapy and surgery for cancers, there is an explicit need to engage with patients and carers in more frank and honest discussion for treatment options. Subsequently, changes in practice with regards to giving a patient with dementia an accurate diagnosis are required, using clear terminology rather than the

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assortment of vague terms such as 'memory impairment', 'forgetfulness' and 'brain failure' that were previously commonplace (Johnson *et al*, 2000).

## **Why tell patients they have dementia?**

The moral doctrine of diagnosis disclosure is derived from a respect for the patient's autonomy as well as the patient's beneficence. Considering the principle of the respect for autonomy (the ability to self-govern and make one's own decisions) and the principle of non-maleficence (the obligation not to inflict harm intentionally) (Beauchamp & Childress, 1994), goals are not necessarily incompatible, but often lead to different decisions about what information is given. The rationale for withholding information rests on preventing harm. It can be argued that truth-telling has become a moral absolute, but non-maleficence must be ensured in disclosure. Considering maleficence, although there may be an association between awareness of cognitive deficits and transient emotional reactions, there is no evidence of long-term psychological damage (Bahro *et al*, 1995; Pinner & Bouman, 2003). Regarding autonomy, as much as patient have a right to be informed of their diagnosis, they may equally wish to waive that right an expression of autonomy. When considering whether or not disclosure would be in the best interest of the patient, one should ensure that there not be undue influence of another person's needs and that emotional factors such as fear or depression that are overwhelming the patient are identified and addressed, so that the patient may face the situation from a position of strength (Drickamer & Lachs, 1992).

## **Reasons for informing patients and carers**

Positive reasons for disclosure range from 'the patients' right to know' and facilitation of future planning to 'taking that once-in-a-lifetime holiday'. It may assist in persuading the patient to accept help and in managing social needs (Pinner, 2000). It enables the issue of driving safety to be addressed (Johnson & Bouman, 1997). Personal affairs such as power of attorney, making wills, choice in future care and living wills with advanced medical directives may be established.

Giving a diagnosis can allay patients' fears of 'going mad' or 'being stupid', if it is seen in the context of a biological disorder or illness rather than negative personality characteristics (Husband, 1999).

Being told the diagnosis may aid the issue of psychological adjustment, enabling patients to share their anxieties with professional and informal carers, thereby relieving some of their uncertainties. Disclosure enables patients to gain support through the difficult process of emotional adjustment and is most important in optimising the therapeutic alliance. It also gives an opportunity for engagement in therapeutic trials. In the unusual case of familial Alzheimer's disease, it also may provide the wider family with information.

Research on the 'use it or lose it' hypothesis suggests that a patient might be able to delay the progression of disease with continued intellectual effort (Orrel & Sahakian, 1995) and that they can certainly make best use of their residual abilities using tactics such as cues, lists and prompts.

Disclosure also provides the opportunity to discuss a care plan, to direct the individual and family to appropriate resources and, in particular now, to gain access to new treatments such as acetylcholinesterase inhibitors.

## **Reasons why practitioners do not disclose the diagnosis**

What are the issues that, in general, cause concern surrounding the disclosure of the diagnosis of dementia to the patient? Practitioners have stated several, including the fear of causing distress and the fear of destroying or reducing hope or motivation. There is also concern about specific detrimental outcomes such as depressive illness, suicide or catastrophic reaction. Some evidence in the literature suggests that many doctors fear that disclosure might precipitate suicide (Rohde *et al*, 1995).

There is no conclusive evidence to justify any of these concerns. There are two studies involving a series of cases of Alzheimer's disease in which the patients were told their diagnosis. In the first, no patients seem to have been harmed by the information, although they did use various psychological mechanisms to protect themselves. These included denial, dissociation of affect, externalisation, displacement and somatisation (Bahro *et al*, 1995). The other showed that patients' most common worries related to fear of others finding out, fears of social embarrassment, long-term dependency needs and not being listened to (Husband, 2000).

Another reason that has given rise to concern is the difficulty of accurate diagnosis. Drickamer & Lachs (1992) challenge this with the statement that, although the histological diagnosis is often uncertain in life, we still have the option of being

'truthful' with our patients, making an honest presentation of the information as it is perceived and known. In many diseases, the diagnosis is not certain until post-mortem study, but this does not stop us from explaining our findings and opinions to the patient.

Reluctance to disclose may reflect a process described by the late Tom Kitwood, called 'malignant social psychology', where devaluing, diminishing, dehumanising and depersonalising the patient with dementia lead to greater disability and dysfunction. Examples include infantilisation, disempowerment and objectification (Kitwood, 1990). Kitwood was at pains to point out that this is not malicious abuse, although it is an everyday occurrence in most care settings and is a 'flawed' response arising from the limited skills most of us exhibit in these circumstances.

### **What do patients want to know?**

The question of what patients with a diagnosis of dementia wish to be told remains largely unexplored. The Fairhill guidelines (Post & Whitehouse, 1995) report a series of meetings involving the testimonies of patients and caregivers about ethical aspects of dementia care and they are firmly of the opinion that a patient with mild dementia should be told the diagnosis. However, there is little research evidence obtaining views of patients themselves on being told a diagnosis of dementia.

One may gain some insight into the views of elderly patients with dementia by examining the views of other elderly peer groups. Studies have looked at cognitively intact older adults in different settings and asked them their views on case vignettes about dementia and a hypothetical diagnosis (Erde *et al*, 1988; Holroyd *et al*, 1996; Pinner *et al*, 2001). These studies showed that a vast majority wished to be fully informed if they were faced with this condition.

An ongoing qualitative research project is underway through the Mental Health Foundation, obtaining the reaction of a small group of patients to being told their diagnosis of dementia. This work stemmed from a document produced for Alzheimer Scotland Action on Dementia on truth-telling (Fearnley *et al*, 1997).

We have recently published the first prospective study to determine the attitudes of patients with early dementia towards the disclosure of their diagnosis and whether there are differences between patients and their carers (Pinner & Bouman, 2003). The study showed that patients with early dementia wished to be fully informed (92%). A majority of carers believed that patients should be told their

diagnosis, which reflects a trend also reported by Holroyd *et al* (2002) and indicates a significant reversal of opinion of carer groups to that previously reported a few years ago. At 1-year follow-up, there were low rates of depression (6%) and no catastrophic reactions were noted; in particular, there were no suicides. For a summary of good-practice points, see Box 1.

### **What do carers want?**

The first comprehensive study in the literature to examine views of dementia carers was carried out in Australia (Brodsky *et al*, 1990). A questionnaire was sent to members of a national carers' organisation. All respondents were aware of the diagnosis. Just over half of the respondents could recall some discussion of management issues and about two-thirds could recall some discussion of prognosis. Thirty-nine per cent of carers claimed that the patient had not been told the diagnosis and roughly 75% of patients had not been informed about management or prognosis. When asked how they would have preferred the diagnosis to be given, 56% said that they would have liked to have been told alone initially and 31% indicated that they would have preferred the diagnosis to have been given to them in the company of the patient.

#### **Box 1 Good practice in the disclosure of prognoses and diagnoses**

##### *Giving 'bad news'*

- Use patient-led communication
- Tailor your approach for each individual
- Remember that this is a dynamic and on-going process
- Identify any potential benefits of knowing the diagnosis
- Instil hope

##### *Diagnosis disclosure – suggested guidelines*

- Use a multi-professional approach to answer questions and make recommendations
- Consider telling patient and carer together
- Allow each separate time to talk and ask questions
- Arrange follow-up meetings to continue discussions
- Discuss how the disease might progress
- Agree a care plan
- Provide written educational materials
- Provide a list of community resources and contacts
- Arrange for further support, e.g. supportive individual or group counselling

A subsequent study examined the views of relatives of sufferers of Alzheimer's disease. Eighty-three per cent of carers expressed a wish that their relative should not be told (Maguire *et al*, 1996). Despite this, 71% of the same carers indicated that they themselves would like to be told if they were developing the illness. A similar, although smaller, survey reported different findings. Fifty-seven per cent of first-degree relatives wished the sufferer to be informed (Barnes, 1997). Reasons for this included not wishing to hide information from loved ones, the belief that the sufferer would probably work it out anyway and the wish to make preparations for their future.

Most of those who opposed disclosure of the diagnosis to the patient felt that telling the truth would cause distress to the patient, that he or she would feel stigmatised, become depressed even to the point of despair and become difficult to manage, although there is little evidence in the literature to support this view. In addition, both patients and family members often use denial as a defence mechanism to deal with a diagnosis. The latest US study investigating caregiver attitudes about diagnosis disclosure was also more positive: 68% of carers agreed that it was a good idea to tell the patient. Caregivers with more education were more likely to believe this. Neither the relationship to the patient, the patient's age, gender or education level nor the degree of dementia were predictive of the caregiver's attitude (Bachman *et al*, 2000).

Patients and carers often wish to know about any potential risk to other family members. It is important to recognise and address their fears relating to the heredity of Alzheimer's disease. Apart from those rare familial forms of the disease, it is important to stress that any increased risk is small and not inevitable, and is multi-factorial in nature. Genetic testing is not helpful in the current clinical context.

As well as discussing the likely diagnosis, a discussion of likely prognosis is also helpful, placed in the context of a late-life illness. Through these open and informed discussions, one can explore with the patient and carer the usefulness of potential treatments.

## How do physicians actually practise?

There is little information regarding carers' views on information given by health professionals. In an early survey addressing this issue, carers reporting that physicians were helpful in providing information on diagnosis, but less so in addressing the psychological and social consequences of dementia (Glosser *et al*, 1985).

A number of studies have investigated physicians' attitudes and practice. Two studies were conducted by Rice (Rice & Warner, 1994; Rice *et al*, 1997), investigating medical practice in this area, one involving old age psychiatrists and one geriatricians. Both suggest a relationship between severity and disclosure, that patients with severe dementia are rarely told and those with moderate or mild dementia are more likely to be told. There were great variations in practice. The practice regarding informing carers differed in the opposite direction.

Gilliard carried out a study of the practice of a number of memory clinics. It was acknowledged that this might not be a typical sample group as patients were generally in the early stages of dementia. Just over half (56%) of the psychiatrists reported telling patients their specific diagnosis, although 25% said they would not routinely discuss the diagnosis nor the prognosis, doing so only if they were directly asked by the patient (Gilliard & Gwilliam, 1996).

Rao (1997) found the diagnosis was commonly told only to the carer, the patient being told in only 37% of cases. Only 39% of carers had shared the diagnosis with the sufferer.

Johnson *et al* (2000) examined current practice and attitudes among geriatricians and old age psychiatrists to disclosure of the diagnosis of Alzheimer's disease. The benefits of disclosure were examined, as were some of the concerns, fears and perceived potential harm. The results suggested that only 40% of specialists in health care for the elderly regularly tell patients their diagnosis and that 20% saw no benefit in telling the patient. However, 72.5% of the respondents reported that they would wish to know themselves if they were suffering from the illness. Interestingly, 50% of those who believed that patients did not want to know wanted to know themselves.

Similarly, a postal questionnaire survey of consultant psychiatrists enquired about their normal practice in giving information about psychiatric diagnoses, including dementia. Only 44% stated that it was their usual practice to tell patients with Alzheimer's disease their diagnosis (Clafferty *et al*, 1998).

There is one study to date investigating the practice of general practitioners (GPs) in disclosing the diagnosis of dementia to their patients. Only 5% of the GPs reported that they always tell patients and 34% that they often tell them. When asked if they tell patients of a diagnosis of terminal cancer, 27% said that they always do and a further 67% that they often do (Vassilas & Donaldson, 1998). As large numbers of patients with dementia are diagnosed in primary care, never seeing a specialist, GPs certainly need to be actively involved in this debate.

## **When and how to tell**

The content, the timing and the manner of the telling must be appropriate for each individual patient, depending on the severity of the dementia and degree of insight. For many patients with early-stage or mild dementia, doubt and fear of the unknown are replaced by a certainty that may be shocking and upsetting at first but is accepted as reality with the passage of time and the establishment of support networks. Most experienced dementia-care professionals have gone through the anticipatory anxiety of 'giving the bad news' of the diagnosis of dementia to patients and their families, only to have the patient say, 'That's what I've thought all along.' As dementia progresses, the erosion of decision-making capacity and competency leads to limited ability to understand the diagnosis and its implications. In the later stages of the disease, the truth will neither benefit nor harm. In the severely affected, disclosure is futile.

It is suggested in the US-based Alzheimer's Association Fact Sheets that, whenever possible, all of the professionals involved in determining the diagnosis of the patient should be present when diagnosis is disclosed, to answer questions and provide specific recommendations to the patient and the family.

In our own clinical practice, we routinely ask the patients whether they would like to know their diagnosis in the company of their carers. In our experience, most patients express the wish to know. Obviously, when having to deliver such bad news, sensitivity, flexibility and discretion are required.

If patients decline the offer of disclosure, we respect their wishes, but ask their consent to disclose the diagnosis to their relatives and/or carers. We also offer the possibility of treatment with one of the cognitive enhancers for their 'memory impairment'. Particularly in this situation, 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 (Pinner & Bouman, 2002). The initial meeting is often overwhelming, so opportunities for follow-up sessions with additional family members should be anticipated.

Sometimes the relatives and/or carers ask that the diagnosis be withheld from the patient. We then first choose to discuss the thoughts and fears that lie behind this wish with the relatives and/or carers and the patient present. Often it transpires that they want to protect the patient from fear and distress, or even a catastrophic reaction. These issues can be addressed through 'patient-led' discussions, which diminishes any adverse emotional effects of disclosing painful diagnostic information, a responsibility all doctors share (Meyers, 1997). It

should be considered an intrinsic part of our work to address the distress and be there for the patient, even if they do not take the diagnosis well.

Our strategies for telling patients their diagnosis are based on our interpretation of the current evidence in the literature. However, these are only guidelines and should be used in both a flexible and a culturally sensitive manner. Further research is required to establish more refined guidelines in this area.

## **Ethical and practical considerations of disclosure**

Except in unusual circumstances, doctors and multi-disciplinary team members should disclose the diagnosis of dementia to patients, because they have a moral and legal right to know. If the patient might have difficulty understanding, you should consider telling the family/carer first. If this is not the case, you should arrange a joint meeting with the patient and the family/carer to disclose the diagnosis. Telling patients and their families/carers the diagnosis can be difficult, since there is currently no promising prognosis for those affected. It might be appropriate to arrange a further meeting for a more in-depth discussion of the diagnosis, treatment, prognosis and available support services.

Disclosing the diagnosis early in the disease process allows patients to continue to live life and play an active role in planning for the future. If you disclose the diagnosis after the dementia has advanced, it may no longer be justified or meaningful to the patient. If patients are informed of the diagnosis early on, they can also be involved in communicating and planning for end-of-life decisions. These plans can apply to issues such as life-prolonging measures and consenting to participate in dementia research, and can be expressed through the preparation of advanced directives. After disclosing the diagnosis, various responses from patients and their families/carers can be expected. These include acceptance of what was suspected, relief at learning what is causing behavioural changes, denial and depression.

## **Conclusions**

Disclosure of a diagnosis of dementia to patients occurs much less frequently than with other illnesses: reports suggest up to 98% of doctors routinely disclose to patients that they have cancer (Holland *et al*, 1987). There is marked inconsistency between medical practitioners' reports of their usual practice on disclosure of a diagnosis of dementia

and their views on the potential benefits of disclosure and patients' wishes. There seem to be three broad reasons for this. The first is uncertainty of diagnosis, which is often given as a reason for non-disclosure. However, with the greater than 90% accuracy of modern diagnostic criteria, this really negates concern about unduly alarming people who have been misdiagnosed (Kukull *et al*, 1990). The second reason reflects a feeling of futility, as the patient may no longer have the ability to understand or make use of the information. This may be true for patients with severe cognitive impairments, but certainly not for patients in the early stages of dementia. These two reasons might explain in part the differences in rates of disclosure of dementia from the rates for other illnesses. The third reason involves protecting the patient from undue distress, believing that hope or motivation might be reduced. This view is similar to that once held with regard to cancer. There is no established evidence that this reaction occurs following disclosure of a diagnosis of dementia and it may be argued that this attitude is an ageist and paternalistic stance taken with little knowledge of the wishes of patients themselves.

Medical practitioners, relatives and carers appear more reluctant to disclose diagnostic information to patients with dementia. This reluctance appears to be operating on a mechanism of a wish to protect, but there is little evidence that patients suffer any long-term harm following disclosure.

Studies investigating older people and people with dementia all reveal high rates of wishing to be fully informed. Established patient and carer forums such as the Alzheimer's Society agree. It is the method of communication and the interplay in roles between doctor, patient and carer that need to be better understood to improve our care delivery.

Our current practice is to obtain the patient's consent to hold a meeting with family members or carers and the patient at which information can be shared. It may be possible to develop practice guidelines to be used by local services and to develop better ways of helping patients through the adjustment period with supportive individual and group counselling. The issue of truth-telling remains an important area for future research, to enable our therapeutic alliance with both patients and carers to be strengthened.

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## Multiple choice questions

- 1 The following celebrities are publicly known to have senile dementia of the Alzheimer type:**
- a Ronald Reagan
  - b Charlton Heston
  - c Iris Murdoch
  - d Michael J. Fox
  - e Tony Blair.
- 2 Useful terminology to use when discussing the diagnosis with patients and their relatives includes:**
- a dementia
  - b Alzheimer's
  - c forgetfulness
  - d brain failure
  - e senility.

- 3 There is evidence that disclosure of the diagnosis to the patient increases:**
- a the suicide rate
  - b depressive illness
  - c autonomy
  - d future planning
  - e tensions within the family.
- 4 Possible adjustment mechanisms patients use following diagnosis disclosure include:**
- a denial
  - b anxiety
  - c depression
  - d displacement
  - e externalisation.
- 5 In the light of current knowledge:**
- a most patients with dementia wish to be told their diagnosis
  - b all practitioners tell patients their diagnosis
  - c it is helpful to see patients alone when disclosing the diagnosis
  - d telling patients that they have dementia is likely to cause a catastrophic reaction
  - e carers would not wish to be told that they might develop dementia in the future.

### MCQ answers

1	2	3	4	5
a T	a T	a F	a T	a T
b T	b T	b F	b F	b F
c T	c F	c T	c F	c F
d F	d F	d T	d T	d F
e F	e F	e F	e T	e F



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