



# Senior

*A Better Quality of Life Through Integrated Mental Health Care*

# Minutes

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## BREAKING THE NEWS: DO PATIENTS WANT TO KNOW THAT THEY

If you had dementia, would you want to know? There is a great deal of debate about whether people with dementia should be told their diagnosis. Most of the debate focuses on the views and experiences of physicians, including psychiatrist's and general practitioners. More recently, the beliefs of family caregivers and non-demented older people have also been explored. However, considerably less attention has been paid to the opinions and concerns of the patients despite the fact that this debate is fundamental to their lives.

We sought to address this issue by examining the perspectives of people who had recently been told they had dementia. We focused on patients' views of the way they were informed of their diagnosis as well as the advantages and disadvantages of receiving early diagnosis.

### ARGUMENTS FOR AND AGAINST DISCLOSURE

Proponents of sharing a diagnosis highlight the importance of maximizing individual difficulties of diagnosing and treating dementia; they emphasize the limited therapeutic options available, the possible distress to the individual that may result from disclosure and the inevitable cognitive decline. There is evidence that such therapeutic nihilism, based on the "myths of early diagnosis," results in a variable array of diagnostic and disclosure practices. Indeed, when the perspectives of practitioners are compared with the views of people with dementia, a communication gap based on lack of understanding is evident. Involving people with dementia in decision-making is of paramount importance; however, we must develop more person-centered approaches to dementia care practice.

### THE PATIENT'S PERSPECTIVE

Our study involved 24 people, ages 44 to 78 years, who had Alzheimer's disease, vascular dementia, Pick's disease or another type of dementia. They were eligible for the study if they had recently been diagnosed with dementia, had been told of their diagnosis and were capable of describing their experiences and giving consent to participate. In most cases patients were interviewed within three or four months of receiving a diagnosis

and half were re-interviewed several months later. Unfortunately, during the interviews it became apparent that five of the participants were not truly aware of their diagnosis. We included their views in our analyses where appropriate, but we did not disclose their diagnosis to them.



### THE MAIN FINDINGS OF THE STUDY ARE:

- All of the participants believed that people with dementia should be told their diagnosis, in most cases as soon as possible. However, they said that disclosure should be tailored to each individual's need for information.
- When informed of their diagnosis, participants experienced a range of feelings including shock, anger, depression and fear. But some also felt that receiving the diagnosis helped to explain and validate their recent behavior and memory difficulties.
- Participants emphasized the need to choose how much information they received and when. Some immediately wanted as much information as possible, whereas others wanted to take things "one step at a time."
- Most participants identified opportunities arising from disclosure of the diagnosis, such as the chance to make legal arrangements and to develop memory aids.
- Patients identified very few advantages to receiving a diagnosis. Although disclosure caused distress; withholding the diagnosis had,

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ironically, also been a source of distress to several participants who reported feeling depressed when they did not know what was wrong with them.

- Some respondents highlighted the importance of information about prognosis and the need for follow-up support from medical staff.
- Social factors played an important role in how people adjusted to the diagnosis. The stronger the support, the easier it was for people to develop positive coping skills.

## OPPORTUNITIES AND LIMITATIONS

Most participants could cite at least one benefit of learning their diagnosis, such as being able to make plans for the future and to take care of

financial legal matters. Another advantage was that patients gained an understanding of the changes within themselves and their behaviors. This helped many adopt a positive approach to the diagnosis. Once they accepted their abilities engaging in activities they had always wanted to pursue (e.g. traveling abroad).

Knowing the diagnosis also inspired some participants to think more actively about ways around the problems they were experiencing. For example, they initiated such practices as establishing a daily routine and using a diary and memory aids. Accessing social support was also important to many.

“I just thought, ‘No sitting crying into my beer. I’ll do my best I can with what I’ve got and have a set routine. It doesn’t mean I can’t shift it about, but you can see I do certain things on certain days and that gives my life a pattern. So I manage that way.”—Mary

“I found it very important to be surrounded by people who know what they’re talking about, know what is wrong with me and what I might do that other people might find strange.”—Dave

The participants did identify some drawbacks to diagnosis. Some lost self-confidence after becoming more aware of their limitations. Patients also had to endure voluntary or involuntary restrictions of their daily activities (e.g. driving). However, these consequences were largely due to the impact of the disease rather than to diagnosis per se and were generally outweighed by the opportunities noted above.

Finally, some participants did suggest that patients with advanced dementia might not be able to understand the diagnosis and thus might not benefit from disclosure. Such cases, they felt, should be evaluated on an individual basis to determine whether disclosure is appropriate.

## CONCLUSION

Evidence indicates that poor or incomplete disclosure not only stems

in part from physicians’ unfounded negative beliefs, but also stands in direct contrast to the opinions of people with dementia themselves. The research reported here reveals that the positive outcomes of diagnosis disclosure outweigh the negative ones, and that withholding the diagnosis can cause distress. The imperative to maximize individual autonomy and to involve people with dementia in decision-making and life choices means that we need to take greater account of their views and experiences. The people who took part in this study clearly felt that it was important that everyone be given the opportunity to choose to have their diagnosis disclosed to them. This view from the previously silent side of the debate has implications for the practice and offers clinicians a chance to understand the patient’s perspective and explore methods for improving disclosure practice.



For more information, contact Dr. Heather Wilkinson, Centre for Social Research on Dementia, Department of Applied Social Science, University of Stirling, Stirling, Scotland, United Kingdom FK9 4LA, E-mail: [HawI@stir.ac.uk](mailto:HawI@stir.ac.uk). A more extensive re-

port on this study, entitled “Tell Me the Truth,” is available at [www.mentalhealth.org.uk](http://www.mentalhealth.org.uk)

**Disclaimer:** The information presented in this newsletter is intended for educational purposes only. It is not a substitute for practical medical advice on any specific situation.

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