

[How to deliver the diagnosis of dementia](#)

Q7: For people with dementia, who should be told of the diagnosis and how should the diagnosis be delivered?

Background

Worldwide, there are estimated to be 25 million people with dementia, Alzheimer's disease accounts for 60% whereas vascular dementia accounts for approximately 30% of the prevalence in low and middle income countries (LAMIC). There is growing evidence that many people with dementia want to know their diagnosis. Older people in community and hospital contexts also have positive views towards disclosure in the event of developing a dementia. There is wide variation in the attitudes of professionals towards disclosing a diagnosis of dementia to patients. The presence of cognitive impairment demands greater attention to the repetition of information and checking of understanding. However, there is evidence that very little time is spent on elaboration or explaining the diagnosis. This is reflected in poor retention of the information for majority of people with dementia (73%) and a significant minority of carers (16%) being unable to report the diagnosis accurately shortly after disclosure. Even when the name of the illness is retained, the diagnosis does not necessarily help people with dementia and family members to understand and make sense of their experiences. Uncertainty about a diagnosis is problematic not only because many people would prefer clarity, but also because uncertainty makes it difficult for people with dementia and their carers to discuss and plan for the future. Optimal management of the condition and adherence to a treatment regimen are also at risk when people are unclear about the diagnosis and its implications.

Population/Intervention(s)/Comparison/Outcome(s) (PICO)

Population:	people with dementia
Interventions:	for health care professionals to promote disclosure
Comparison:	care as usual
Outcomes:	improved quality of care

List of the systematic reviews identified by the search process

INCLUDED IN GRADE TABLES OR FOOTNOTES

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Lecouturier J et al (2008). Appropriate disclosure of a diagnosis of dementia: identifying the key behaviours of 'best practice'. *BMC Health Services Research*, 8:95.

Narrative description of the studies that went into the analysis

Lecouturier et al, 2008 reported that there are no intervention studies to improve diagnostic disclosure in dementia have been reported to that time. The objective of study was to identify the range of disclosure behaviours using literature review, interviews with dementia people and caregivers and a consensus panel of health and social care professionals representing the range of disciplines involved in disclosing a diagnosis of dementia. The literature search identified 293 articles of which 109 were considered relevant to the process of disclosure. Also, 10 face-to-face interviews: four with people with dementia and six with informal carers were carried out. Finally, eight panelists completed the questionnaire.

Results of analyses, including statistical summaries (as appropriate)

Interviews were conducted with four people with dementia and six informal carers. Eight health social care professionals took part in the consensus panel, From the interviews, consensus panel and literature review 220 behaviours were elicited, with 109 behaviours over-lapping. The interviews and consensus panel elicited 27 behaviours supplementary to the review. Those from the interviews appeared to be self-evident but highlighted deficiencies in current practice and from the panel focused largely on balancing the needs of people with dementia and family members. Behaviours were grouped into eight categories: preparing for disclosure: integrating family members; exploring the patient's perspective: disclosing the diagnosis; responding to patient reactions; focusing on quality of life and well-being; planning for the future, and communicating effectively.

Narrative conclusion

This study has highlighted the complexity of the process of disclosing a diagnosis of dementia in an appropriate manner. It confirms that many of the behaviours identified in the literature (often based on professional opinion rather than empirical evidence) also resonate with people with dementia and informal carers. The presence of contradictory behaviours emphasizes the need to tailor the process of disclosure to individual patients and carers. These combined methods may be relevant to other efforts to identify and define complex clinical practices for further study.

Reference List

Lecouturier J et al (2008). Appropriate disclosure of a diagnosis of dementia: identifying the key behaviours of 'best practice'. *BMC Health Services Research*, 8:95.

From evidence to recommendations

Factor	Explanation
Narrative summary of the evidence base	<p>In an attempt to identify best practice with respect to diagnostic disclosure, a research group in UK carried out a systematic review of the literature on "breaking bad news with respect to a range of clinical conditions, including dementia", 10 open-ended interviews with people with dementia and their carers on their experiences of diagnosis and a consensus panel of 8 health professionals involved in imparting diagnosis. The researchers attempted to identify a comprehensive list of behaviours relating to disclosure highlighting those which were endorsed as good practice in the literature, open ended interviews and health professional consensus.</p>
Summary of the quality of evidence	<p>It is unclear what proportion of the 108 papers identified were related to dementia diagnosis disclosure. It is also unclear what is the proportion of 108 papers in terms of expert opinion vs. empirical evidence. The triangulation approach used to identify best practice is the best methodology considering the nature of data available. However it appears noteworthy there is no experimental data regarding the different approaches.</p> <p>Probably very low quality evidence</p>
Balance of benefits versus harms	<p>The high level of agreement between data from the literature, interviews and consensus panel suggests that although much of the literature focuses on breaking bad news to people with cancer, it is nevertheless highly relevant to disclosing a diagnosis of the dementia. The interviews not only provided behaviours unique to people with dementia and their carers but also confirmed the need for intervention by highlighting deficiencies in current practice. The panel placed greater emphasis on preparing for disclosure and managing the role of family members in the disclosure process.</p> <p>Eight key domains of good practice for disclosing dementia diagnosis were identified- preparing for disclosure; integrating family members; exploring the patient's perspective; disclosing the diagnosis; responding to patient reactions; focusing on quality of life and well-being; planning for the future; and</p>

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	communicating effectively. The person being assessed should be asked if they, and/or others wish to be told the diagnosis. They should then be provided with information about the signs and symptoms of dementia, course and prognosis, available treatments, local care and support services.
Values and preferences including any variability and human rights issues	There may be differing views in the families; they may differ with regard to decision making responsibilities. There are cultural variations in views and preferences. Medico-legal issues may vary from country to country, including financial and testamentary capacity and driving safety. Human rights and associated ethical issues should also be considered.
Costs and resource use and any other relevant feasibility issues	-
Final recommendation(s) People with dementia and their family members should be told of the diagnosis subject to their wishes in this regard keeping in mind the cultural sensitivities and after some preparatory work to determine their preferences. If diagnosis is disclosed it should be accompanied with relevant information appropriate to culture and understanding of people with dementia and family members, and with a commitment of ongoing support and care that can be provided by health and other services. Strength of recommendation: STRONG	

Update of the literature search – June 2012

In June 2012 the literature search for this scoping question was updated. No new systematic reviews were found to be relevant.