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STEVEN M.B. ARISS, ERYK GRANT, MURNA DOWNS,  
BRENDON FERNANDEZ

Bradford Dementia Group, Division of Dementia Studies, School of Health Studies, University of Bradford, 25 Trinity Road, Bradford, BD5 0BB, UK. [email: e.grant1@bradford.ac.uk], [email: m.downs@bradford.ac.uk], [email: drphilip@edith59.fsnet.co.uk]

RUTH GALLAGHER

Alzheimer's Society Bradford Branch, 16–18 North Parade, Bradford, BD1 3HT, UK.  
[email: ruth@alzheimers-bradford.co.uk]

DEBRA CHERRY, MICHELLE BARCLAY

Alzheimer's Association of Los Angeles, 5900 Wilshire Blvd, Los Angeles, California 90036, USA.  
[email: michelle.barclay@alzarsb.org], [email: debra.cherry@alz.org]

## **A model for disclosure of the diagnosis of dementia**

ELS DERKSEN, MYRRA VERNOOIJ-DASSEN,  
PHILIP SCHELTENS AND MARCEL  
OLDE-RIKKERT

### **Introduction**

Diagnostic disclosure is considered a basic intervention in dementia care for both patient and carer (see the article by Vernooij-Dassen, Derksen, Scheltens & Moniz-Cook, this issue). Although it is standard practice in the Netherlands for clinicians to disclose a diagnosis of dementia, there are no guidelines available on the issue. In addition, medical records tend to include very little information on the reactions of patients and carers to disclosure. Previous research has shown that while people with dementia and carers appreciate disclosure, they are less satisfied with the information that they receive (van Hout, Vernooij-Dassen, Hoefnagels & Grol, 2001; Vernooij-Dassen, Van Hout, Hund, Hoefnagels & Grol, 2003), although a third of them do receive further advice in subsequent meetings (Vernooij-Dassen et al., 2003). Memory clinics connected to the three Dutch *Alzheimercentra* have responded to the results from this research by setting up a quality improvement process that focuses on diagnostic

disclosure. A model has been developed to enhance the last phase of the diagnostic process, which consists of a disclosure meeting with the medical doctor and a counselling meeting with a nurse or nurse practitioner. This model is based on the principles of 'breaking bad news' (van Spaendonck & Kraaimaat, 2004).

This article describes in detail the disclosure meeting with the physician. However, we stress that after anything with such far-reaching consequences as a diagnosis of dementia, additional meetings must also form part of the disclosure process. These meetings concentrate upon the way the person with dementia and the carer have processed news of the diagnosis. In addition, after identifying a person's needs for care and support, advice about care options is also given.

### Disclosure meeting

In the disclosure meeting, the physician discusses the diagnosis and explains the results of the physical and psychological screening to the person with dementia and their carer. These results must be presented in ways that relate to the concerns of the person with dementia (van Spaendonck & Kraaimaat, 2004). In the case of diagnostic disclosure in dementia, the physician has to adapt the process of disclosure and information sharing to the cognitive capacities and understanding of the person with dementia. Before the actual disclosure takes place, the physician has to be prepared; Figure 1 summarizes the preconditions for the disclosure meeting.

The diagnosis of dementia generally comes as bad news. Even if people with dementia and their carers view the diagnosis as confirming their suspicions, until the point of disclosure they have been hoping for another explanation for the cognitive problems (Derksen, Vernooij-Dassen, Gillissen, Olde-Rikkert, & Scheltens, 2005).

**Phase 1: Introduction** After the physician introduces him or herself, he or she will set out the agenda for the meeting. The introduction should be limited to one or two sentences to help the person with dementia focus on the reason for the meeting. It is important to be aware of some of the pitfalls that should be avoided in the introductory phase. These include:

- **Social talk:** this can confuse the person with dementia. It may be difficult for them to concentrate on the actual content of the meeting.
- **Long introductions:** if the physician starts to repeat a person's medical history as part of the introduction, the person with dementia may lose their concentration.
- **New information:** an introduction should only contain information that has already been given which can be used to frame the conversation.

1. **Time and space:** the physician has enough time available for the disclosure meeting. The time needed will vary but 30 minutes seems to be a good estimate. The meeting must take place in a quiet room with no interruptions.
2. **Continuity in person:** the same physician who met the person with dementia before in the diagnostic process must disclose the diagnosis.
3. **Preparations:** the physician must be aware of the expectations of the person with dementia and their carer concerning the diagnosis. The physician knows how to disclose 'bad news' and how to connect the diagnosis to the memory complaints of the patients.
4. **Social environment:** patients with cognitive problems often will be accompanied by their family or friends. In case of a person with dementia with severe cognitive problems, this is to be recommended. It is important to address the person with dementia directly in the disclosure meeting.
5. **Continuity in care:** the nurse (practitioner) who will discuss the diagnosis and its consequences in an additional meeting needs specific information on the disclosure meeting.

Figure 1 **Preconditions for the disclosure meeting**

**Phase 2: Sharing the diagnosis of dementia** The diagnosis of dementia should be disclosed in short and clear terms. The words 'dementia' and 'Alzheimer's Disease' can be used. It is often helpful to first explain that 'dementia' is a disease of the brain. This helps people to understand that cognitive problems and changes in behaviour have a physical cause. Pitfalls to be avoided in this phase include:

- **Jargon:** the physician uses medical specialist terms.
- **Drop-wise (or drop-by-drop) information:** The physician gives information so gradually that the disclosure becomes more puzzling to the person with dementia.

**Phase 3: Space for emotions** In this phase, people with dementia and their carers need space to express their emotions. Techniques that can be used to create this space include:

- **Tolerance of silence:** the person with dementia has the opportunity to react with tears, expressions of disbelief or passiveness.

- **Reflection:** the physician can help the person with dementia to give a name to their emotions. They should not try to convince the person with dementia with arguments in the face of disbelief or denial. It is better to reflect denial by saying, for example, ‘You can’t believe this is happening to you?’

Creating time for emotions has a purpose; only after the person with dementia and their carer have overcome the first shock can they open themselves to further explanations. It is also important to realize that feelings of sadness and anger will probably only reveal themselves much later. Most people with dementia, like the majority of us, are able to control their emotions at the point of receiving news of their diagnosis.

**Phase 4: Further explanations** Now the physician can also use ‘describing’ terms to explain more about the diagnosis. The following subjects can be discussed in this phase:

- **Clarification of the results:** the physician can give additional information about the test results and connect the information to the cognitive problems of the person with dementia.
- **Direct consequences:** discussion can take place on the direct consequences of the diagnosis, for example, restrictions concerning driving.
- **Answering questions:** it is important that after the actual disclosure of the diagnosis further questions can be raised. However, it is probable that, depending on their expectations about the diagnosis, both the person with dementia and their carer are unlikely to retain this information fully.

Throughout the disclosure meeting, but especially in this phase, it is important to keep some ‘golden rules’ in mind, as presented in Figure 2.

**Phase 5: Continuity of care** In this final phase of the disclosure meeting it is important to emphasize the person with dementia’s remaining capacities. If possible, the physician can talk a little about the prognosis for the near future. The opportunities for medical treatment may also be mentioned. However, one should be cautious about raising expectations about the effects of any treatments. In most cases, it will be sensible to discuss this topic in a separate meeting. At the end of the meeting, the physician can hand out specific written information. This can help the person with dementia to remember what has been said and gives them an opportunity to discuss it with others.

Assessment of the person with dementia’s needs for care and the carer’s need for support, including identification of any stressors for the caregiver

1. Restrict yourself to the main issues.
2. Be aware of using confusing statements on 'negative' and 'positive' results.
3. Try to outline the short-term changes to the patients and carers. Do tell them that it is difficult to predict the course of dementia.
4. Check if and how the information has been understood.

Figure 2 **Pointers for verbal communication**

and their ability to take on this role must be part of the disclosure (Derksen, Vernooij-Dassen, Gillissen, Olde-Rikkert, & Scheltens, in press). For this, the physician can refer to the counselling meeting with the nurse. To ensure continuity in care, the nurse needs to know how the person with dementia received news of the disclosure so the physician must report these issues in the medical record.

### **Counselling meeting with nurse (practitioner)**

The counselling meeting with the nurse takes place between two and four weeks after the disclosure meeting. The aims of this meeting are to:

- give the person with dementia and their proxy the opportunity to express their feelings and experiences about the impact of the diagnosis;
- assess their need for care and support; and
- give them care advice.

The same preconditions set out in Figure 1 are relevant for this counselling meeting. The nurse focuses upon the remaining capabilities of the person with dementia and encourages them in their coping behaviour. The model involves a joint meeting between the person with dementia and their carer, thereby showing them that dementia is a topic that can be talked about. Furthermore, it is important that this meeting is tailored to the needs of the person with dementia and their carer. Several topics can be discussed in this session, as shown in Figure 3. In the case of a person with severe behavioural problems and a carer who is experiencing difficulties with their role, a separate meeting can be necessary with each of them. The meeting will end with individualized ('tailor made') care advice. The nurse will add this advice to the discharge letter to the GP because of their co-ordinating role in care for people with dementia living at home. Frequently, more intensive support is needed after disclosure in such a situation. The GP can refer the person with dementia and their carer to a community mental health service.

- Perception of receiving the diagnosis of dementia
- Diagnostic expectations: confirmation or surprise?
- Did the person with dementia and carer share the diagnosis with others?
- Assessment of specific problems and needs for care
- Information about dementia and care
- ‘Tailor made’ care advice and information about care providers

Figure 3 **Topics for a counselling meeting**

Part of the diagnostic process also involves the nurse planning a meeting with the carer, in which the carer’s sense of competence and the person with dementia’s behaviour are discussed. Together with the information about the person with dementia’s and the carer’s perceptions of the disclosure, it gives the nurse a starting point for the needs assessment. Affirmation of carers’ achievements can also be a great support (Derksen et al., in press).

### **Training sessions**

The disclosure model will become part of standard practice within the memory clinics in the Alzheimer Centres in Nijmegen and Amsterdam. Part of the implementation involves two sessions of training for both physicians and nurse practitioners. In this training, the model is discussed and physicians participate in role-play about diagnostic disclosure. Furthermore, physicians receive feedback on their performance in the disclosure meeting by videotaping a real-life situation. In a separate meeting the nurse (practitioners) are instructed about the content of the counselling meeting.

### **Conclusions**

We developed a new method for disclosing the diagnosis of dementia by adapting the model of ‘breaking bad news’ (van Spaendonck & Kraaimaat, 2004). We feel that when supporting people with dementia, it is especially important to hold on to the order of the phases in the disclosure meeting and to take enough time for each phase. All the principles of ‘breaking bad news’ are applicable to diagnostic disclosure in dementia, but specific attention should be given to two issues. First, it is significant to help the person with dementia concentrate on the purpose of the disclosure meeting through a good introduction. Second, we stress that, as with any other person, it is important to address the person with dementia as a partner in the conversation.

This model aims to improve the diagnostic disclosure in dementia. Using this disclosure model offers the opportunity to systematically pay attention to the disclosure procedure, while using accepted principles of bad news communication. In our ongoing study, we will evaluate the effects of this basic intervention on the patients' well-being and the carers' burden and sense of competence.

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**ELS DERKSEN, MYRRA VERNOOIJ-DASSEN**

Alzheimer Centre Nijmegen, Centre for Quality of Care Research, Radboud University Medical Centre, PO Box 9101, 6500 HB Nijmegen, The Netherlands.

[email: e.derksen@kwazo.umcn.nl], [m.vernooy-dassen@voha.umcn.nl]

**PHILIP SCHELTENS**

Alzheimer Centre Amsterdam, VU Medical Centre, PO Box 7057, 1007MB Amsterdam, The Netherlands. [p.scheltens@vumc.nl]

**MARCEL OLDE-RIKKERT**

Alzheimer Centre Nijmegen, Department of Geriatrics, Radboud University, Nijmegen, The Netherlands