

A new model for breaking bad news to people with intellectual disabilities

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Background:

Existing models for breaking bad news do not work well for people with intellectual disabilities (ID).

Objectives:

To develop a model for breaking bad news news that meets the communication needs of people with ID.

Design:

A two-phase qualitative study: (I) Focus group meetings, online focus groups and one to one interviews; (II) Structured feedback from participants and other stakeholders.

Participants:

109 participants were purposively selected: 21 people with mild/moderate ID, 28 family carers, 26 ID professionals and 34 general health professionals.

Outcome measure:

Feedback on a preliminary model for breaking bad news to people with ID was collected from 60 participants and other stakeholders to assess relevance and acceptability, before the model was finalised.

Results:

Breaking bad news is best seen as a process, not an event. Bad news situations usually constitute a wide range of discrete items or chunks of information. 'Building a foundation of knowledge' is central to the model. Three other aspects should be considered at all times: capacity, people and support.

Conclusions:

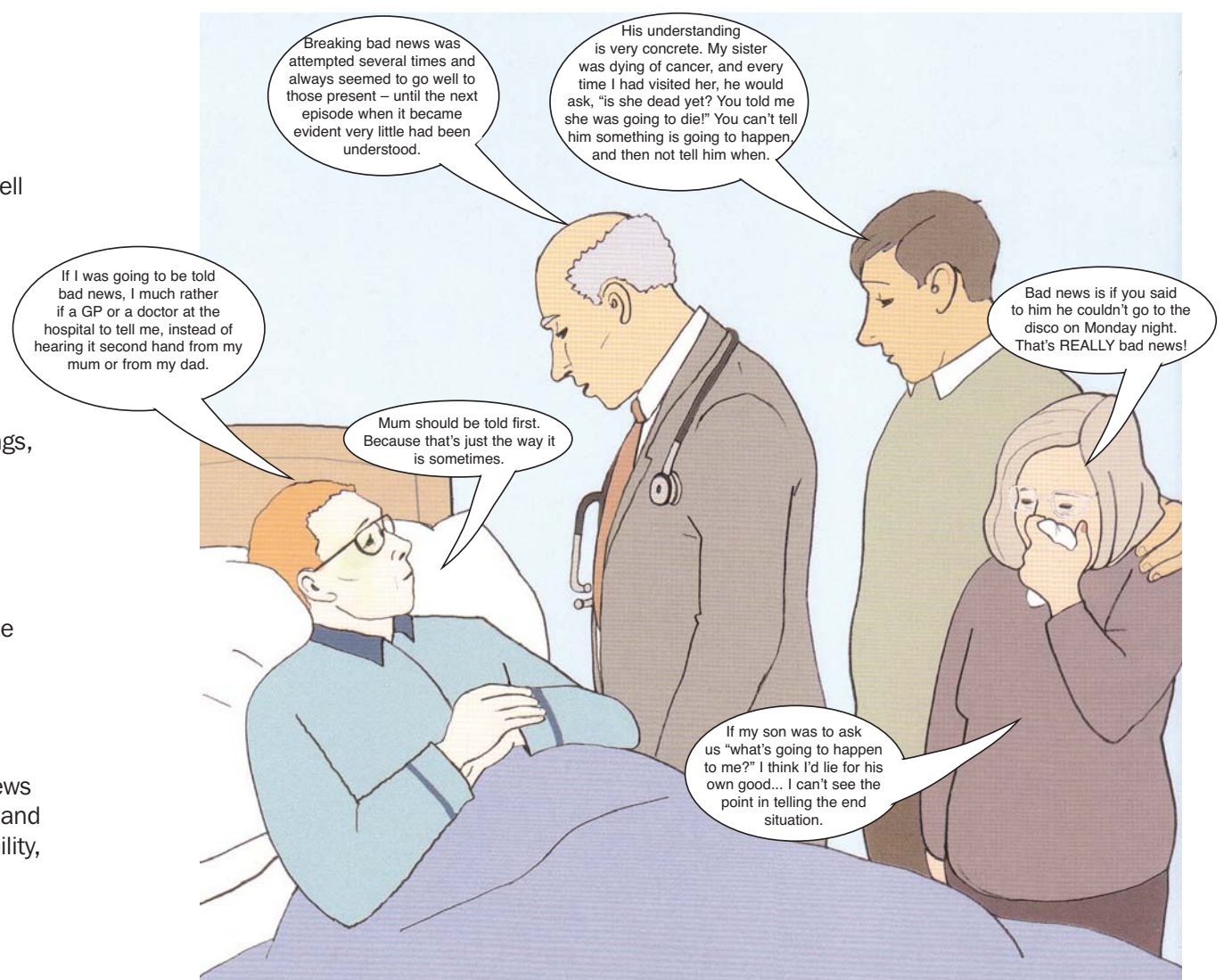
Patients who have ID do not easily process verbal information in a clinical setting. The new model for breaking bad news to people with ID needs to be tested in practice using robust outcome measures. The model's relevance to wider patient groups should also be evaluated.

Building a Foundation of Knowledge is central to the model.

Gradually and over time, the person with intellectual disabilities builds his/her understanding of the way his/her situation is changing because of the bad news. The people around him/her help with this, by giving small, singular chunks of information that make sense to the person. This does not have to done by talking: much of the information will be understood through experience.

The following three aspects need to be considered at all times

- **Capacity and understanding** taking account of the Mental Capacity Act
- **The people involved** including family, partners, friends, paid carers and professionals
- **The support needed** by everyone involved, including information, emotional, social, practical and spiritual support



Background knowledge

What is happening now

What will happen in the future

Example of the model in practice

- This shows all the different chunks of information that are related to the news that someone with ID has cancer which cannot be cured and which will be treated palliatively (supportive care and relief of symptoms). The prognosis is limited.
- Understanding that "I have cancer" and that "I am going to die" are only two chunks of a huge amount of information and changes. This information will not make sense without other supporting knowledge (including, for example, a concept of time and future).
- Nobody has the full picture. No-one has all the possible chunks of knowledge. Helping the person build his/her framework of knowledge is a team effort!