

Training scenario

Breaking bad news to people with intellectual disabilities

The scenarios below involve two people with intellectual disabilities, Jeremy and Christina, who each face the same cancer diagnosis and treatment choices. However, because of their very different (dis)abilities, the way they are helped to understand their situation has to be different.

Your task is to decide in each scenario:

- Jeremy/Christina's current 'framework of knowledge'. What is their current background knowledge? What do they understand about what is happening right now? What do they understand about the future?
- How much more could they be helped to understand? What 'knowledge chunks' could, and should, be added to their current framework of knowledge?

The bad news situation: 'You have cancer'

You have cancer of the oesophagus (food pipe). The tumour is blocking your oesophagus, so you can't swallow. There are two treatment options:

- (a) An operation to remove the cancer. This would leave you with a permanent PEG tube (a feeding tube that goes through your skin straight into your stomach). You will never be able to eat normally again. There is a chance of around 30% that this will cure the cancer.
- (b) Putting in a stent (artificial tube) to un-block your oesophagus. You will be able to eat, but the cancer will still be there, and you will eventually die from this.



Jeremy Wilson

Jeremy Wilson is 45 years old and has moderate intellectual disabilities. He lives in his own flat with daily support and has a job in the kitchen of a pizza restaurant, where he chops salads. He has an active social life with lots of friends and is close to his family whom he visits often. He has a reasonable concept of time and some understanding of abstract concepts, including dying. He knows cancer can kill you: his aunt died of breast cancer.

Jeremy has been very tired and has not been able to go to work for several months. He loves his food and has been very upset since he lost the ability to swallow a couple of weeks ago. He is currently fed through a tube directly into his stomach. Jeremy hates his tube and is longing to eat pizza. Until now, he has not been told that he has cancer. He has an appointment to see the hospital consultant and has been told that his family should come with him for support. His family has been told about the cancer, but not about the treatment options.

Jeremy goes to the appointment with his brother and sister. The cancer diagnosis and treatment options are explained to Jeremy by the consultant and a specialist nurse. The intellectual disability nurse (who has been visiting him at home) is there too. Jeremy can't really understand what the doctor is saying, but he knows that something serious and important is going on: he hardly ever sees his brother, and his sister is crying.

Jeremy's family does not want the operation. They think that it would be too difficult for Jeremy to lose the ability and prospect of eating altogether, and they think the odds of a cure are too low. They are aware that Jeremy should be involved in this decision if at all possible, and want him to, but don't know how to go about it. Back home, Jeremy asks whether he is going to die like his aunt...

Christina Doherty

Christina Doherty is 45 years old. She has moderate intellectual disabilities and autism. She lives in a residential care home. She works in the main office of the residential care organization three days a week, fulfilling clerical tasks which she enjoys immensely.

Christina has no concept of time, and (as far as staff can tell) no understanding of cancer, or of the complexities of illness and the universality of death. She speaks and understands short, simple sentences.

Christina has exactly the same cancer diagnosis and outlook as Jeremy. She, too, is told by the doctor with her family present. She shows no sign of having understood any of the information, although she shows concern for her sister crying.

Christina's current framework of knowledge is much smaller than Jeremy's. It is not well supported and there are a number of gaps. She doesn't understand why she can't eat or why she needs the feeding tube (and hates it), and she doesn't really understand why her family has come (but likes this). She is confused and needs a lot of support to help her understand what is going on. She hates changes in routine and wants to go back to her job. She doesn't want to visit the hospital.

There are not many 'knowledge chunks' present, and it takes Christina a while to accommodate and adapt to each new one. There are a number of 'chunks' that she would not be able to understand, as they don't fit her current experience. This includes most information of what will happen in the future. She would not be able to understand that she has cancer and that she may die of this, because she cannot see the cancer and she doesn't feel as if she's dying...