

Guidance for managers and trainers in intellectual disability services

How can we talk about death and dying in our teams?

Communicating about illness, death, dying and bereavement is difficult in general, not just in relation to people with intellectual disabilities. Many people working in intellectual disability services have hardly ever talked about death and dying with colleagues, friends and family – let alone with people with intellectual disabilities.

This guidance is designed to help get “death conversations” going. Talking to colleagues and peers first will help staff feel more comfortable in communicating about death and loss with the people they support.

These are ideas for discussion topics in team meetings or staff training events.

- Groups of between 4 and 8 people work well.
- Take around 30 minutes to discuss one of the topics.
- There are no right or wrong answers. The most important thing is that you are talking together, listening to each other and sharing experiences.
- If there is more than 1 group (e.g. at a training event), ask someone to feed back a couple of key discussion points to the full group.

General discussions about death

Present the group/team with one of the following topics.

Instruct people to let their mind wander and speak freely...

- ***What does this topic make you think about?***
- ***When / where / how have you been confronted with this topic?***

If there is time, you may also talk about:

- ***What, in relation to this topic, are you doing WELL already?***
- ***What have you heard from others that you can take back to your work place?***
- ***What help do you (and your team) need, in relation to this topic?***

1. “John has intellectual disabilities. He has a terminal illness but doesn’t know this yet.”
Should John be told that he is going to die?
2. “John’s support worker has known him for many years. She is deeply upset about his terminal illness, but she thinks: *I have to be strong for John. He mustn’t see me being upset.*”
How does bad news affect staff and families?

3. “John has many close friends, who also have intellectual disabilities. They all live nearby, in homes supported by staff. They knew that John was ill, but not that he was going to die. Now John has died...”

Who should tell John’s friends that John has died? When? How?

4. “One of John’s friends is Jenny, who has profound intellectual disabilities. Jenny does not communicate in words, and she does not understand words. John has just died.”

Can you help people with severe or profound intellectual disabilities understand that someone has died? How?

5. People are often fearful about communicating issues of end of life care with the individuals with LD they know and support, their families, friends and peers.

What aspects would you personally be worried or frightened about, and why?

6. **How would you describe what dying is to someone without intellectual disabilities?**

(Suggestion: Turn to the person next to you and explain death! What words would you use?)

Specific discussions about one of your clients

If the team has experience of supporting someone with intellectual disabilities who experienced death, dying or bereavement, you could talk together about...

- What did you find **most difficult** about the situation?
What were/are you **most frightened** about?
- **How much do you think the person understood/understands?**
(For example: Does he/she understand what death means?)
Should (or could) he/she be helped to understand more?
What experiences can you give him/her to help him/her understand more?
- **How does this person usually cope with bad or difficult news?**
How does he/she cope with change?
What help does he/she need to prepare for (and cope with) change?
- **How can you support each other?**
What other help or support do you need (perhaps from managers or outside professionals)?

For more ideas: The book “How to break bad news to people with intellectual disabilities” by Irene Tuffrey-Wijne (Jessica Kingsley Publishers, 2013) has “Thinking Points” at the end of each chapter. These can be used in team discussions.