

Research Question

What are the experiences of people with ID who have a relative or friend with cancer?
What are their support needs?

Methods and sample

- 21 adults with ID who have had a relative/friend with cancer
- Almost all of the relatives/friends had died of cancer
- 3 focus groups (n=17), 4 face-to-face interviews
- Each focus group met 4 times
- Data collection methods included story-telling, role play and Nominal Group Technique ("voting" for the best support strategies)

Findings

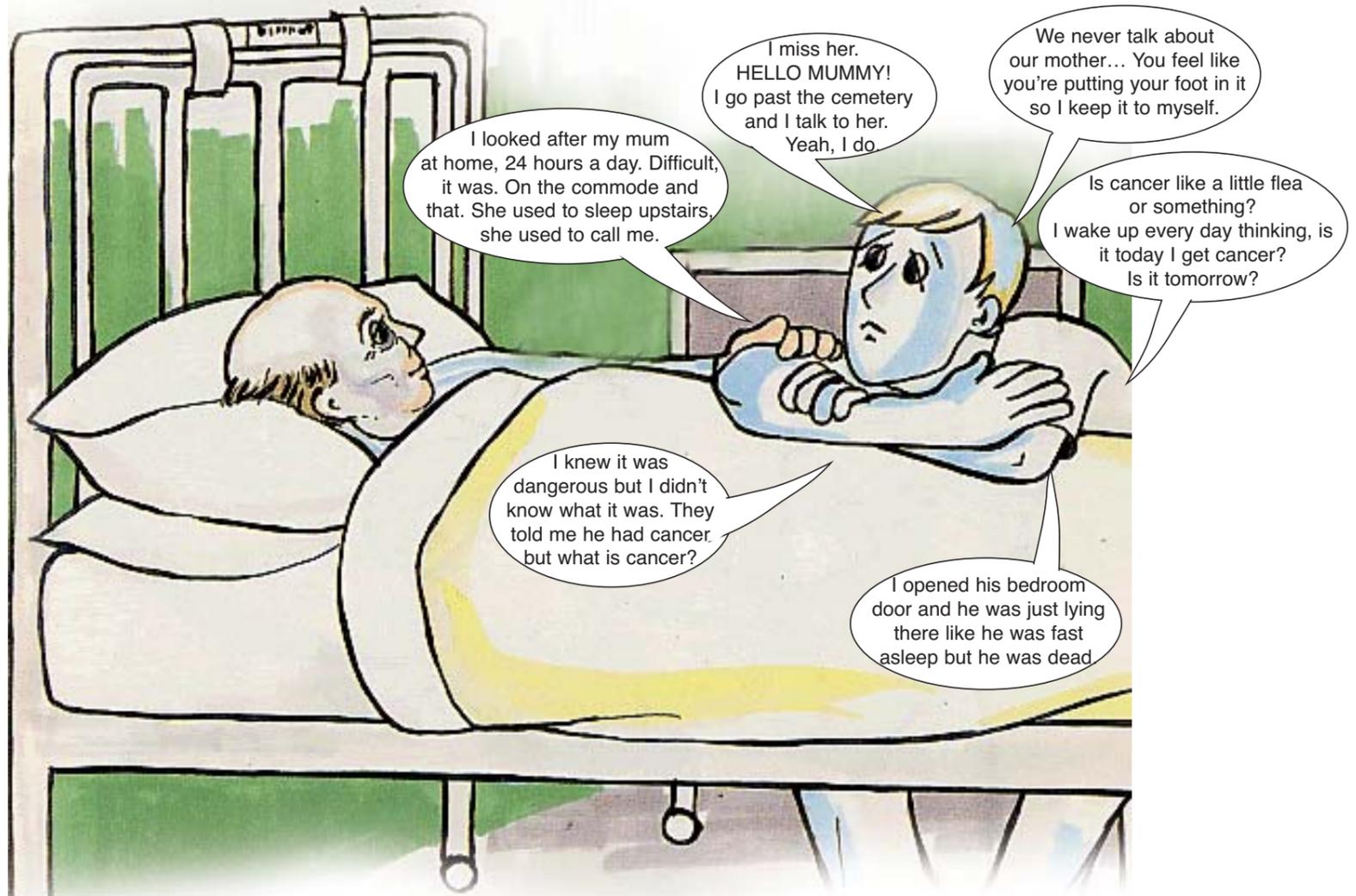
4 main themes:

- **Protection and inclusion.** Those who had not been told about the patient's illness felt excluded. Being told that someone had cancer did not necessarily mean that the person with ID had understood the implications.

- **Coping with cancer.** People with ID had vivid memories of events and feelings. They worried about their families. Several had become carers themselves.
- **Understanding cancer.** People with ID lacked knowledge about cancer and wanted to know more. Many were worried that they themselves would get cancer.
- **Someone to talk to.** People with ID would have liked to share their feelings and questions with family, friends or professionals, but most had not done so.

Conclusions and recommendations

- People with ID need to be included as an active member of the family unit.
- Their need for support should be assumed – they will not ask for it, and many will not receive adequate support from their families and carers. Staff should demonstrate availability and willingness to provide support.
- Helpful support measures include a listening ear and a supportive presence.
- Cancer and palliative care professionals should collaborate with learning disability professionals.
- Staff should familiarise themselves with accessible information materials, and learn how to use them.



What helps?

See below for the most helpful support strategies, suggested and voted on by the participants

