

UNDERSTANDING DECISION MAKING AT END OF LIFE

WE ARE
MACMILLAN.
CANCER SUPPORT

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1. Macmillan Cancer Support
2. Revealing Reality

Background

There is emerging evidence that helping people living with a terminal diagnosis plan for their future care can offer many benefits. This planning often takes the form of Advance Care Planning, or Anticipatory Planning in Scotland (ACP), and is a voluntary process. This research aimed to understand how people living with a terminal diagnosis, their loved ones, and health and social care professionals experience end of life communications and decision making.

'You're so scared of saying the wrong thing, or damaging spirits, but more harm is done by not saying anything at all.'

Palliative care nurse

'I haven't made any plans or communicated any plans to anybody. I don't know why. Probably because I don't really know what I want or what I would like.'

Isobel, person living with a terminal cancer

Methods

The research had two distinct qualitative phases:

- Stage one: a multi-site ethnographic study exploring ACP service provision and implementation in five areas across the UK through observation and interviews with professionals.
- The second stage of the research involved ten in-depth ethnographies of people with cancer who had a terminal diagnosis. The ethnographies were spread over four months and typically involved two face-to-face visits and follow-up telephone calls.

Results

There are a number of barriers to delivering ACP. Many are partly due to the challenge of knowing when and how to start conversations around planning.

This research found that many people living with a terminal cancer diagnosis are unaware of ACP and don't know how to have conversations around planning. Although many naturally begin making plans around social or financial issues, for example making a will, or ensuring their children will be financially supported, these plans are rarely progressed into an ACP.

Similarly, some professionals feel they don't have the expertise or capacity to approach planning conversations. This is partly due to the difficulty of discussing death and end of life issues and a fear of upsetting their patients. However, those experienced in having ACP conversations spoke of their importance and the benefits future planning has for people living with a terminal cancer diagnosis, such as enabling patients to have a sense of control.

Conclusion

This research has highlighted that, though there are currently many barriers to putting ACP into practice, conversations around end of life planning can be beneficial to patients, professionals, and the wider healthcare system.

Together with Macmillan

REVEALING REALITY

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