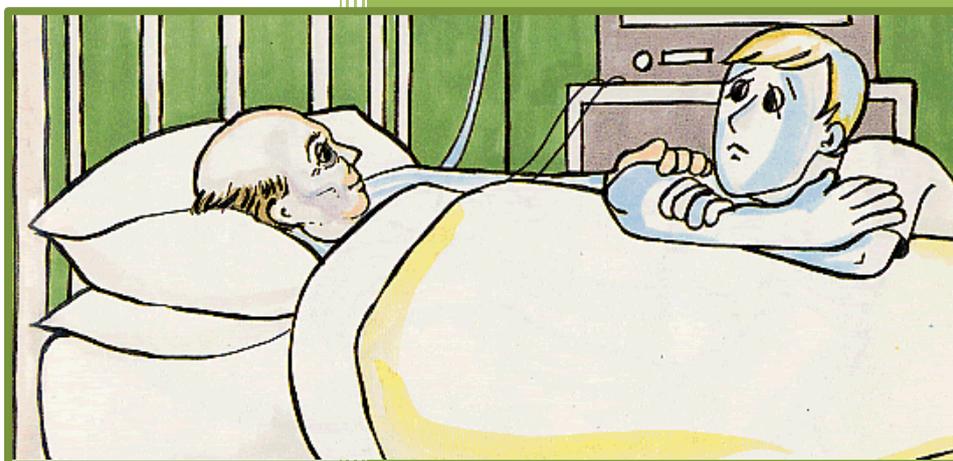


**WE ARE
MACMILLAN.
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A research study
commissioned by
**Macmillan
Cancer Support**

**Supporting people with learning disabilities who
are affected by a relative or friend with cancer**



FINAL REPORT

November 2011

AUTHORS

Irene Tuffrey-Wijne *Principal Investigator*

Nikoletta Giatras

Gary Butler

Amanda Cresswell



St George's
University of London

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Irene Tuffrey-Wijne (RN, PhD)
St George's University of London
6th Floor Hunter Wing, Division of PHSE
Cranmer Terrace
London SW17 0RE
UK

Nikoletta Giatras (PhD)
St George's University of London

Gary Butler
St George's University of London

Amanda Cresswell
St George's University of London

We welcome comments on this report.

Contact Dr Irene Tuffrey-Wijne, tel +44 (0)20 87255497, email ituffrey@sgul.ac.uk

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We were supported by a Research Advisory Group, which met four times during the study. The group included people with learning disabilities, family carers, cancer and palliative care professionals, learning disability professionals and academics. A full list of members can be found in Appendix 9.1. The group provided enthusiasm, contributed ideas, gave feedback on our progress and on our preliminary findings, and supported dissemination.

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1. Executive Summary

1.1 Background

It is likely that most people with learning disabilities will be affected by cancer of family or close friends at some point in their lives. This paper reports on a study of the impact of cancer on carers, relatives and friends who have learning disabilities.

The research team consisted of Irene Tuffrey-Wijne (Principal Investigator), Nikoletta Giatras, Gary Butler and Amanda Cresswell. Gary and Amanda both had learning disabilities. We used sometimes experimental and largely successful methods in working together and ensuring that all were able to contribute. This is described extensively in this report, as it forms part of our data collection and analysis.

1.2 Aims and objectives

The aim of this study was to explore the experiences of adults with learning disabilities who have a relative or friend with cancer.

The objectives were to:

- Identify the cancer information and support needs of people with learning disabilities who have a relative or friend with cancer.
- Identify the barriers people with learning disabilities face to receiving adequate information and support when a relative or friend has cancer.
- Make recommendations for (i) practice, (ii) the development of resources and (iii) future research, to ensure that people with learning disabilities are adequately supported when a relative or friend has cancer.

1.3 Methods

Data collection took place between March 2010 and March 2011. Three focus groups were convened; each group met four times. Four one to one interviews were conducted with participants who were unable to take part in the focus groups for practical reasons but were keen to contribute to the study. A total of 21 participants took part. All were adults with learning disabilities who had some verbal communication skills and who had a relative or friend with cancer in the past ten years. Participants had to be able to give informed consent. Meetings were audio recorded and transcribed verbatim. Notes and reflections of the researchers were added at this stage and formed part of the data set. The data were analysed using thematic content analysis. Data management was supported by Nvivo 8 for qualitative analysis. The research team was supported and guided by a Research Advisory Group, which included a range of stakeholders, including people with learning disabilities.

1.4 Findings

1.4.1 Four main themes

Protection and inclusion

Several families seemed to not have shared information with participants as a way of protecting them from the bad news. This had the effect of participants feeling excluded as a family member, causing distress or anger that, in some cases, persisted years later. Participants agreed that they had the right to know like the rest of their family members. Some participants' families did not hide the cancer diagnosis from them, although being told that someone had cancer did not mean that the participant had understood the implications. Those who were included in what was happening, and knew what was going on with their ill relative or friend, seemed better able to get closure.

Coping with cancer

Many participants had vivid memories of their loved one being ill and dying. The experience of coping with someone who was ill and watching them die involved feelings of worry and general distress. Participants expressed a range of worries and concerns, including: worry

that the cancer patient might die; concern and worry about the rest of the family, and their own feelings of responsibility within the family; and worry that they themselves might get cancer. Seven participants reported having become carers themselves. Participants viewed themselves as able to understand, help and to be responsible, but they seemed to receive no credit or support for this. Most participants had suffered a bereavement through cancer, and this affected their coping and their contributions to the study. They were coping with loss and grief; for several, this was still raw, even many years after the bereavement.

Understanding cancer

There was an overwhelming need for information about cancer from all participants. They had many questions and worries, highlighting the lack of information available to them.

There was general ignorance about cancer. Participants expressed the need for more information about cancer and proposed that this could include pictures to make it easier for both doctors and nurses to explain, and for people with learning disabilities to understand.

Someone to talk to

The majority of participants found it helpful to talk with someone, whether it was a friend, relative or professional. Most participants said that they would look to their families for support in the first instance. However, they also seemed to be protecting their families from their own distress, and found that they could not actually ask their families for support. They did not know how to approach professionals, and sometimes feared that they would be dismissed as they had been from their families.

1.4.2 Helpful support strategies

The participants proposed a range of support strategies. These were summarised in nine statements and presented to the focus group participants. The strategies that were perceived to be most helpful were those that involved the presence of someone who could offer support, to talk to, to answer questions, and to support the family. Less weight was given to practical support measures (such as accessible information). The participants ranked the strategies in order of preference, as follows:

1. *Someone to talk to about my feelings and worries*
2. *Someone to support the rest of the family*
3. *My family, carers and doctor should tell me everything*
4. *Someone I can ask questions about cancer*
5. *A support worker to be with me*
6. *Other people with learning disabilities to talk together about our experiences*
7. *Easy words and pictures to explain cancer*
8. *Photos of the ill person to help me think and talk about them*
9. *Someone to help look after the ill person*

1.5 Discussion of key findings

Information needs

There was an unsurprising lack of knowledge and understanding of cancer among the participants, and a desire to know more. In order for people with learning disabilities to have sufficient information in a way they can understand, they need other people who: (a) recognise the information need; (b) wish to meet this need; and (c) know how to meet it, which includes finding accessible information. Our study found that for people with learning disabilities, having someone who can recognise their need and is willing to meet those needs is more important than having access to accessible information.

The need for support

The extent to which participants felt isolated and in need of emotional support was striking. This was not primarily a desire for straightforward cancer information, but for someone to share worries and concerns with. Most people with learning disabilities depend on their immediate families or care givers for support, but we found that at times of crisis caused by cancer, families may not be able to provide such support. People with learning disabilities often try to protect their own families from distress. They don't know where else they can go for support, and are unlikely to seek support from professionals. Many participants in this study wanted to have someone they could talk to, which may well reflect their verbal ability. However, we speculate that the need for 'someone to be there' for them is a need that can be generalised to all people with learning disabilities, including those with more severe

expressive and receptive communication difficulties. This could simply be a supportive presence for those who do not use words.

People with learning disabilities as carers

Growing numbers of people with learning disabilities are becoming carers of elderly relatives within the family home, with high levels of ‘mutual caring’, where neither person could live independently without each other’s support. Without support at points of crisis, people with learning disabilities are less able to fulfil this role, and their needs may escalate to the point where their usual support networks break down.

The impact of bereavement on people with learning disabilities

Many of the focus group sessions and interviews were strongly influenced by the effect of participants’ grief for loved ones. Issues around bereavement, in particular parental bereavement, can be particularly complicated for people with learning disabilities.

Complicating issues include people’s understanding of death; a lack of acknowledgement for the loss, grief or mourner; complications in early parental attachment; and difficulties in keeping the memories of the deceased alive. We also found complications arising from being protected from bad news and from outward expressions of grieving. Family members may find it very difficult to provide adequate support, and many people with learning disabilities would benefit from outside bereavement support.

1.6 Conclusions and recommendations

1.6.1 Conclusions

Many people with learning disabilities cope very well in manners similar to those of the general population. Complications arise mostly from a lack of recognition of normal needs. Difficulties arise from complex family relationships, and from issues around ‘protection’ and ‘mutual caring’. Complications also arise from difficulties in processing new and complex information.

Support needs are more important than information needs. The most important support and information needs are: to be included and not protected from the situation; to have someone who can listen to questions and concerns, and who can offer a supportive presence; to have access to information that is easy to understand; and to have sensitive bereavement support.

Barriers to receiving adequate information and support include:

- People with learning disabilities tend to ‘keep quiet’, and often do not ask questions or express true feelings to those who might be able to help.
- People with learning disabilities lack insight into the roles of outside professionals, and how they might help.
- There is a lack of opportunities for people with learning disabilities to share their feelings and experiences with peers.
- People with learning disabilities are not given enough recognition of their emotional capacities.
- People with learning disabilities lack access to easy-read information materials, even if they exist; they rely on others to enable them to access such materials.

The barriers we have identified are based on the perspectives of people with learning disabilities, which was within the remit of our study. Some further barriers have not emerged directly from this study, but can be speculated following reflection on our findings and on the available literature. These include a lack of recognition by professionals that people with learning disabilities need their support; uncertainty among health care professionals about how to communicate with people with learning disabilities; and insufficient support for families in helping relatives with learning disabilities cope with the situation.

1.6.2 Recommendations

Recommendation 1

If a cancer patient has a relative, partner or close friend with learning disabilities, whose life will be affected by the illness, these should be offered professional support *as a matter of course*. Staff should aim to increase their understanding of the individual with learning disabilities, and any special issues or coping strategies they may have. They should talk to

the cancer patient and other relatives and to the community learning disability team about ways in which the person with learning disabilities can be supported.

Recommendation 2

Staff should be aware that family or carers do not necessarily provide adequate support or information. They should offer support to families, paid care staff and learning disability professionals, so that these are better able to support the person. This includes passing on factual information about the cancer; advice on including the person in what is happening; and advice on normal emotional responses.

Recommendation 3

Professionals should check whether any relatives or friends with learning disabilities have themselves taken on caring responsibilities. If so, they should be involved as partners in the provision of treatment and care for the patient, and offered adequate support. Professionals should also check whether the patient has anybody within their social circle who is reliant on their care or support.

Recommendation 4

Professionals should be aware of the high likelihood that people with learning disabilities experience complicated grief, and ensure that adequate support is in place.

Recommendation 5

Training on 'learning disability' should be made available for health care staff. Such training should include: the impact of learning disability on people's lives; communication with people with learning disabilities; and the use of accessible information materials.

Recommendation 6

Further accessible materials should be developed to help people with learning disabilities make sense of a range of difficult situations and experiences.

Recommendation 7

In order to understand more fully the support needs of family and friends with learning disabilities, further research is needed in a number of areas, including: demographics; the

needs of people with severe and profound learning disabilities; the perspectives of other stakeholders; and the effectiveness of accessible cancer information materials. Such research should include people with learning disabilities, both as participants and as members of the research team.

2 Background

2.1 Introduction

Good communication and support for carers and families during patients' illness and after death are important aspects of high quality care, recognised in UK cancer and palliative care strategies^{5:6}. The impact of cancer on life, including the impact on family and others, was identified as a top research priority by cancer patients themselves in the Macmillan Listening Study⁷. In response to this, Macmillan Cancer Support instigated a programme of user-led research around the impact of cancer on everyday life. This included 'supporting the needs of family carers and exploring the impact of cancer on friends'. The study reported in this paper was set up as part of this programme, focusing on the impact of cancer on carers, relatives and friends who have learning disabilities. The study aims to explore the cancer experiences of relatives and friends who have learning disabilities, and to understand their support needs.

This section sets out the background to the study. We give a definition of learning disabilities, as well as some numbers: demographic details and information of how cancer affects people with learning disabilities. We describe in some detail the background to involving people with learning disabilities in research, as this is a crucial aspect of our study. Finally, we describe the knowledge base of the needs of people with learning disabilities who have a relative or friend with cancer.

2.2 Learning disability

2.2.1 Definition of learning disability

Terminology has changed over the decades and is still changing. In this report, the term 'learning disabilities' is used, as this term is recognised and acceptable in the UK. Outside the UK, the term 'intellectual disabilities' is often used, as 'learning disabilities' has a

different meaning in some countries (for example, in the US ‘people with learning disabilities’ include ‘people with dyslexia’, which is not the case in the UK).

In the ICD-10 definition, ‘mental retardation’ (yet another term for learning disabilities) indicates an IQ of below 70 and impairment of a range of skills⁸. The ICD-10 makes the often-used distinction between mild, moderate, severe and profound intellectual disabilities (see Box 1). The definition used in this report is that of the UK Department of Health¹, which states that there are three aspects to the definition of learning disabilities: (1) the presence of a significantly reduced ability to understand new or complex information, to learn new skills (impaired intelligence); (2) a reduced ability to cope independently (reduced social functioning); (3) which started before adulthood, with a lasting effect on development. This definition is preceded by the important statement that people with learning disabilities are ‘people first’.

Box 1 Degree of learning disabilities: IQ and skills range

Degree of learning disabilities	Approximate IQ range	Impairment of skills
Mild	50 to 69	Likely to result in some learning difficulties in school. Many adults will be able to work and maintain good social relationships and contribute to society.
Moderate	35 to 49	Likely to result in marked developmental delays in childhood but most can learn to develop some degree of independence in self-care and acquire adequate communication and academic skills. Adults will need varying degrees of support to live and work in the community.
Severe	20 to 34	Likely to result in continuous need of support.
Profound	under 20	Results in severe limitation in self-care, continence, communication and mobility.

Taken from the ICD-10 definition of ‘Mental Retardation’ (World Health Organisation, 1992) (p.369-370)

In practice, it was not possible in our research to be sure whether potential participants met the criteria for learning disabilities. Most people with learning disabilities do not have their IQ recorded. Whilst the presence of learning disabilities was undisputed for those with more severe cognitive impairments, it was more difficult to assess in those with less pronounced cognitive impairments. We therefore adopted a ‘social systems perspective’ as the main

criterion for determining whether people could be said to have learning disabilities and were therefore eligible to participate in the study. This followed the practice of other researchers, such as Booth & Booth⁹ in their study of parents with learning disabilities, who state that ‘the only practical decision rule we could follow was to select parents who at some time in their lives, not necessarily currently, had been in receipt of health, education or social services specifically intended for people with learning difficulties’ (p.416).

2.2.2 Demographics

Estimates of how many people have learning disabilities vary, as such information is not held by central government departments in the UK, nor can they be reliably taken from large-scale population based surveys. In the White Paper *Valuing People*¹ (2001) it was estimated that 145,000 adults in England have severe or profound learning disabilities, and 1.2 million have mild or moderate learning disabilities (2.5% of the general population). A more recent report (2008) of people with learning disabilities in England gives an estimate of 828,000 adults (2% of the general population), 177,000 of whom are known users of learning disabilities services. Most people with learning disabilities (55%) live with parents, and a further 12% with other relatives. Around 15% of people with learning disabilities live in residential care homes. It is estimated that the number of people with learning disabilities in England within the 50+ age range will increase by 53% between 2001-2021².

2.3 Cancer and learning disability

Around one in four people in the general population die of cancer³. Our study is concerned with people with learning disabilities who are a relative or friend of a cancer patient, but as their own circle of friends is likely to include people with learning disabilities, it is worth considering cancer incidence among people with learning disabilities. There are no mortality statistics for people with learning disabilities. Studies carried out in the 1990s suggested that up to 16% of people with learning disabilities died of cancer⁶³ although real figures may be higher due to under-diagnosis. Cancer incidence is rising among people with learning disabilities, particularly in the older learning disability population⁶⁴.

Given the large proportion of people with learning disabilities (67%) who live with their parents or other relatives, and given the fact that many people with learning disabilities are ageing, it is likely that significant numbers of people with learning disabilities have themselves become carers of elderly parents. Many of those who live in residential care homes will have an ageing peer group. Although there are no empirical data on how many people with learning disabilities have experienced cancer in their close circle of family or friends, it is very likely that most will have had someone close to them living with, or dying from, cancer.

2.4 Involving people with learning disabilities in research

2.4.1 The research team

This study involved people with learning disabilities both as participants and as co-researchers. Our research team consisted of **Irene** Tuffrey-Wijne (Senior Research Fellow and Principal Investigator), Nikoletta (**Niki**) Giatras (Research Assistant), **Gary** Butler (Co-researcher) and **Amanda** Cresswell (Co-researcher). Both Gary and Amanda have mild/moderate learning disabilities. In a study of this nature, the researchers themselves are a key aspect of the process. Their relationships with each other and with the participants influence both data collection and analysis, and this influence must be acknowledged. Therefore (and for ease of reading) we will refer to the researchers by their first name in the rest of this report.

All team members were paid researchers at St George's University of London. Amanda and Gary had no formal research training; Irene and Niki had both completed a PhD. Gary and Irene had worked at the university for a decade, on a programme of studies involving people with learning disabilities and end-of-life issues. Niki and Amanda were newly in post. Amanda had personal experience of living with cancer, having survived lymphoma and coped with a range of cancer treatments. She had been a participant in Irene's previous study investigating the experiences of people with learning disabilities who had cancer¹⁰, before being offered the position of co-researcher.

2.4.2 Participants with learning disabilities

It is now accepted within the academic world that people with learning disabilities are not only capable of being reliable informants with valid opinions who have a right to express them, but that they are in fact the best authority on their own lives, experiences, feelings and views¹¹. This is a huge shift, coinciding with the move from a medical model towards a social model of disability in the 1980s. As Walmsley¹² points out, until then people with learning disabilities were ‘tested, counted, observed, analysed, described and frequently pathologised, but never asked for their views’ (p 188). ‘User views’, if sought at all, were commonly solicited through parents and professionals¹³.

There is now a large body of research that has included people with learning disabilities as participants, but research around sensitive issues like cancer, death and dying remains limited. Significant ethical and methodological challenges may have prohibited meaningful involvement of a vulnerable group in research around such issues in the past⁴. However, there is evidence to suggest that people with learning disabilities can and want to be involved in such research^{14;15}. The question is therefore not *whether* people with learning disabilities should take part in sensitive research, but *how*. We will describe this in further detail in Section 3 (Methodology).

2.4.2 Co-researchers with learning disabilities

During the late 1990s, self-advocacy organisations such as ‘People First’ began to demand inclusion not only as research participants, but as researchers who contribute to both the design and the execution of research. By the beginning of this century, major grant-giving bodies had made user-involvement a prerequisite for funding. National UK guidelines on good practice in active public involvement in research state that people with personal experience relevant to the research topic should be involved from the beginning, and that this goes beyond simply taking part in the study. Such involvement could mean helping the researcher to identify and ask the right questions in the right way; making sure that health and social care research is relevant to patients, people using services and the public; and getting involved in the research process itself, whether designing, managing, undertaking or disseminating research¹⁶. Macmillan Cancer Support’s user-led research programme is a

clear example of such involvement working in practice. In our study, ‘user involvement’ did not only mean the involvement of cancer patients, but first and foremost the involvement of people with learning disabilities.

There is a growing number of studies in which people with learning disabilities are grant holders, advisors, researchers, authors and disseminators¹⁷. However, improving the practice of designing and planning and seeing through a research project in which people with learning disabilities are involved remains a challenge¹⁸. There is some debate about the extent to which people with learning disabilities can be involved in high-quality research in a way that is meaningful and not just tokenistic. We believe it is important to be as transparent as possible about researchers’ contributions, and will attempt to do so in this report.

2.5 People with learning disabilities who have a relative or friend with cancer

The research proposal has come out of Irene’s previous research findings, in particular a three year ethnographic study which involved 13 participants with learning disabilities, ten of whom died of cancer. It became clear that the needs of their peers were generally overlooked, but there was evidence of their distress. The following quote demonstrates this. Pete had severe learning disabilities and was dying of lung cancer; Maureen was a fellow resident in his care home.

‘Towards the end of Pete’s life, he was no longer able to manage the stairs and spent a few nights sleeping in the sitting room. A long-term, trusted member of staff at Maureen’s day centre told the support workers that Maureen had expressed fear and distress about this. Maureen was frightened that she would be in the room when Pete died. She had said: “It’s alright for you, you go home to your own house at the end of the day. I have to sit there and watch it.” The home manager was shocked to hear this: he wasn’t aware of the extent of Maureen’s distress. “She is really generous with Pete,” he said. “She never complains, and never moans at him.”’¹⁹ (p. 128)

Another study showed that people with learning disabilities who are relatives of cancer patients could be excluded from knowledge about cancer by both families and professionals, and that this lack of involvement and information could cause distress. One participant was in tears when he explained about the lack of information when his father died of cancer:

‘What I can say, that doctors, nurses, they’ve not told me what’s been... they did say to me that he had cancer, but they didn’t tell me why he had to go through with it, they didn’t tell me what it’s like (...) I’ve got learning difficulties, how would they let me know what’s happening? You know? And that’s the big thing about it (...) That’s what really hurts me.’²⁰ (p. 112)

A study of the challenges faced by palliative care staff who support patients with learning disabilities showed that these challenges include the support of relatives who have learning disabilities, with one palliative care physician commenting on a patient with learning disabilities who had died:

‘We had the additional problem after he actually died, trying to explain to [family members, who also had learning disabilities] that he was dead. They couldn’t get that clear in the head either... they kept coming to visit at the same time every day because they got into a routine.’²¹ (p. 496)

Other researchers have also found that people with learning disabilities are often excluded from information when a relative has cancer. The death of a parent can therefore come as a surprise, when other relatives without learning disabilities may well have been able to anticipate it^{22;23}. Bad news of cancer is often not given to people with learning disabilities, or is given in a confusing way^{24;25}.

There has been no published research to date where the experiences and support needs of cancer patients’ relatives and friends who have learning disabilities are the focus. This gap in knowledge has led us to develop this research project.

2.6 Aims and objectives

The aim of this study was to explore the experiences of adults with learning disabilities who have a relative or friend with cancer.

The objectives were to:

- Identify the cancer information and support needs of people with learning disabilities who have a relative or friend with cancer.
- Identify the barriers people with learning disabilities face to receiving adequate information and support when a relative or friend has cancer.
- Make recommendations for (i) practice, (ii) the development of resources and (iii) future research, to ensure that people with learning disabilities are adequately supported when a relative or friend has cancer.

3 Methods

3.1 Introduction

It is a challenge to select appropriate methodologies for studies involving participants with learning disabilities, and this has perhaps received insufficient attention. Within the proliferation of research reports, it is rare to find a reflection on the considerations for selecting a particular methodology, or an analysis of the effect of the participants' limitations (most obviously their intellectual and communication impairments) on the academic rigour of the research. Research papers often include very limited information about the nature of participants' learning disabilities, their support needs within the study, communication difficulties, sampling methods and the precise way in which data were collected. They are, however, crucial if we are to judge whether a study is not only inclusive but also academically robust. We will therefore report extensively on all aspects of our methodology, with further detail provided in appendices. This will hopefully enable other researchers to benefit from the lessons we have learnt and replicate what has been effective.

We also believe that some aspects of our research methods have relevance for clinicians working with cancer patients and their relatives who have learning disabilities. On more than one occasion, a nurse or support worker attending our focus group sessions commented how the ways in which we elicited participants' experiences, questions and thoughts would be useful to them in their clinical role. As it is part of a professional's role to find out what support is needed by someone who may not volunteer information or communicate their needs in conventional ways, it might be helpful to consider using aspects of our data collection methods.

This section provides:

- a summary of the research methods (3.2)
- a detailed description of the participants (3.3) and how they were recruited (3.4)
- a general description of the use of focus groups (3.5) and interviews (3.6) with people with learning disabilities, and a specific description of how we used these methods

- details of how we analysed the data, in particular how we worked together on this as researchers with and without LD (3.7)
- ethical considerations (3.8)

Reflections on the methodology, and the lessons learnt, will follow in Section 5.5.

3.2 Summary of research methods

The primary data collection method was through focus groups. Three focus groups were convened (two with six participants; one with five participants); each group met four times. The groups were facilitated by Irene, Gary and Amanda, whilst Niki took notes. Four one to one interviews were conducted by Irene with participants who were unable to take part in the focus groups for practical reasons but were keen to contribute to the study.

Each meeting was audio recorded and transcribed verbatim. Notes and reflections of the researchers were added at this stage and formed part of the data set. Data collection took place between March 2010 and March 2011. The data were analysed using thematic content analysis.

Niki and Irene conducted the initial stages of the analysis, but the final analysis was undertaken by all four researchers. Data management was supported by Nvivo 8 for qualitative analysis⁶².

3.3 The research participants

3.3.1 Inclusion and exclusion criteria

The inclusion criteria were as follows:

- Adults (aged 18 or over) with learning disabilities. We used the ‘social systems perspective’ as described in Section 2.2.1 to determine whether a potential participant had learning disabilities.

- Some verbal communication skills (able to understand and speak in short sentences). This was assessed by Irene during the consent process.
- Having had a relative or friend with cancer in the past ten years, and since the participant was aged 18 or over.

The exclusion criteria were:

- Those unable to give informed consent
- Recent bereavement of close relative/friend (in the past six months).

Assessments of whether or not someone should participate were made on an individual basis. This assessment involved Irene, the participant, and (if available) a professional or carer who was closely involved in the participant's daily life. How recently someone had been bereaved, for example, was not necessarily the best indicator of how appropriate it would be for the person to take part in the study. For people with learning disabilities, time needs to be considered flexibly. A bereavement that has happened several years earlier may be experienced as recent²⁶. Conversely, a bereavement in the past six months may not be as overwhelming as expected, depending on the nature of the participant's relationship with the deceased. Similarly, the provision that the experience of living with someone with cancer should be within the last ten years proved to be somewhat haphazard. This criterion was made following reviewers' concerns about retrospective bias and memory distortion. However, in practice we found that several participants did have such experience in the past decade, but had also lost a parent to cancer much earlier; these early experiences were very much 'alive' for them. We have included those experiences in the data.

3.3.2 The participants in this study

Appendix 9.2 gives a full overview of participant characteristics, including sex, age and who in their social circle had cancer.

Participant characteristics

There were 21 participants. Their characteristics were as follows:

- 17 women and four men
- aged from 19 to 63 (mean age: 42; median age: 44)

- All participants had mild/moderate learning disabilities. It fell outside the remit of this study to establish the exact nature of participants' learning disabilities, but it appeared to us that participants 2, 3, 4, 5, 6, 7, 8 and 14 had moderate learning disabilities and more severe limitations in language skills; the other participants had mild learning disabilities and were well able to communicate verbally
- Seven participants had Down Syndrome
- Participants' living situation was as follows: in the parental home (4); with other relatives (1); alone (3); with spouse (2); with son (1); supported living (4), all with varying levels of support from a community nurse and/or support with daily living tasks; in a group home (2); unknown to us (4).

The cancer patients

It was sometimes difficult to establish exactly who in the participants' social circle had cancer, and how long ago this occurred. Professionals who knew the participants did not usually have the exact information. Even if they did (for example, they may have known that someone had lost a parent to cancer, and they may have known roughly how long ago this was), we found that several participants mentioned further friends or relatives with cancer during the course of the study, who may have affected them as strongly. In total, the participants mentioned 40 cancer patients between them. Almost all of these had died; only five of the cancer patients had survived. One participant's husband (who also had learning disabilities, and whom she cared for) was terminally ill (see Appendix 9.2).

Because some participants had difficulty with the concept of time, we could not establish reliably how long ago the cancer patients had died, particularly if it was before their current manager or nurse (our 'gate keepers') were in post. There appeared to be a wide variation in time frames. Some participants talked about a cancer death in their teens, several decades ago; others had experienced a cancer death less than a year ago.

Most, but not all, participants had lived with the cancer patient in the parental home, their own home (with a partner, for example) or in a group home. An inclusion criterion on the original protocol stated that the participant should have shared a home with the cancer patient. However, in practice we allowed flexibility, as some people with learning disabilities were strongly affected by someone's cancer despite not living with them. One

woman, for example, had an uncle who died of cancer. The uncle lived next door and she was extremely close to him. She was included in the study and provided some salient data.

3.4 Selection and recruitment

3.4.1 Obtaining informed consent

We produced an easy-read, pictorial participant information sheet (Appendix 9.3). We also produced an information DVD where all four researchers explained together what the study involved (Appendix 9.4). The purpose of the DVD was to supplement the participant information sheet. It did not contain all the necessary information, but it introduced the research team and the research topic to potential participants.

Participants were recruited through approaching the managers at learning disabilities charities, day centres and self advocacy groups directly. A call for participants was also posted on two on-line learning disabilities forums. A liaison person, such as a learning disabilities nurse or manager, distributed the study information materials and invited those interested to attend an information meeting. At this meeting, Irene and Gary showed the DVD and answered any questions. During this information session, we stressed how difficult the topic could be for some people, and how it might make people feel sad. We explicitly used the words ‘cancer’ and ‘die’. Participants were encouraged to take the information sheet home and discuss it with partners, friends, families and/or support staff.

Three potential participants decided not to participate after attending the information session, despite initial interest; they indicated that the topic would be too upsetting for them after all. Most participants seemed to understand the potentially distressing nature of the research topic and consented to taking part in spite of this – or maybe even because of this. For example, one woman cried when she watched the DVD, remembering her mother who had died of cancer. She said she wanted to come to the focus group because she wanted an opportunity to talk about what had happened. Participants agreeing to participate signed informed consent. Ongoing consent was ensured by emphasising after each session that

participants could withdraw; none did so, although some participants missed some of the sessions for other reasons.

In case of interviewees, Irene went through the information sheet and obtained informed consent before the start of the interview.

It is worth noting that in our experience, both in this study and in our previous research, participants with learning disabilities don't always wait for the consent procedure to be completed before sharing their most salient experiences. Rather than using the information materials to decide whether or not they wish to take part, participants often use them as a prompt to start talking about the topic, and can find it difficult to return to the matter in hand (the consent procedure).

3.4.2 Recruitment details for all participants

Focus groups

Group A (Participants 3-7): We contacted the manager of a large self advocacy group that met regularly once a month, drawing people from across London. The manager invited the whole group (around 20 people) to attend the information session, without screening them for a background of cancer experience. She thought that there might be five or six who had close experience of cancer. She was surprised to find that more than half of the group volunteered enthusiastically ('I really want to be in that cancer study') and started talking about their experiences immediately. Six of them were purposively selected. One participant left the group after the first meeting, as it emerged that his experience with cancer did not include a close friend or relative (as the manager of the group had thought at first). He is not included in the analysis. Monthly meetings were held at the group's usual venue, with one or two support workers also attending.

Group B (Participants 8-13): We contacted the manager of a London-based drama group of people with learning disabilities. The manager selected six potential participants she felt were suitable to take part because of their experience of cancer. When they attended the information session, they had already discussed the information sheet with the manager and

had a good understanding of what the study involved. All agreed to participate. Weekly meetings were held at the group's usual venue, with one support worker also attending.

Group C (Participants 16-21): We were contacted by a learning disability community nurse just outside London, who had seen information about the study on an on-line forum. She arranged for nine potential participants to attend the information session, drawn from the caseload of several learning disability community nurses. All had been bereaved of a close relative or friend; when asked what they thought the study was about, several responded 'grieving'. We therefore took time to explain that the focus of the study was on their experiences at the time of their loved one's illness and death. At the end of the information session, three people withdrew, stating that they did not wish to discuss this topic after all. Weekly meetings were held at the premises of the learning disability community team, with up to five support workers and learning disability nurses also attending.

Interviewees

All interviewees were sent the study information sheet and consent form before Irene met with them. Formal consent was taken at the start of the interview.

Participant 1 approached Irene directly in person before the start of the study, having met the team and heard about the study during the dissemination process of a previous study. Irene discussed the study by telephone before the interview.

Participant 2 was put forward by a learning disability social worker who had heard about the study through professional networks. Irene sent her the study information, and she passed it on to the participant. Before the interview, Irene discussed the study with the participant by telephone. During the interview, the participant's husband was also present (he had learning disabilities and had recovered from cancer); a support worker was present in the house but not in the room.

Participant 14 was put forward by her mother, who had seen the call on an on-line forum. The participant's verbal communication was limited to single words and very short sentences, so all initial consent procedures (including explanations of the study and passing on the participant information sheet) were done by the mother. The participant lived in a residential care home, but the interview took place at her mother's home with the mother present.

Participant 15 contacted Irene directly via email, having seen the call on an on-line forum. We did not manage to include her in a focus group, so she travelled to St George's University where Irene interviewed her.

3.4.3 Difficulties with recruitment

Setting up the focus groups was more difficult than anticipated. The difficulty of getting past 'gate keepers' who believe that cancer is too sensitive a topic for people with learning disabilities to discuss has been noted before^{20:22}. We found that the problem was not that gate keepers were reluctant to put people with learning disabilities forward for a study about cancer (most were supportive of the study and agreed that it was an important), but rather, that they didn't know who of their clients had been affected by cancer and were reluctant to ask. Some did say that they were concerned how taking part in the study might affect their clients. This is in contrast with Group A, where more potential participants than expected had relevant experience and volunteered for the study, having been given the opportunity.

Interviews were included for practical rather than methodological reasons. The interviewees were very keen to contribute to the study, and would have liked to attend a focus group, but this was not possible for various reasons:

- One interviewee had personal links with a member of the research team which could have compromised the focus group dynamics.
- We were unable to organise a focus group that suited the needs of another interviewee.
- Two interviewees were unable to undertake regular journeys to the focus group meetings; they lacked adequate support to enable them to do so.

We found that the logistical difficulties of organising focus groups that are not drawn from already existing groups (such as day centres or self advocacy groups) can be prohibitive. The mother of participant 14 said:

'She lives with one other person and has a support provider, but I have to say they're useless. They are not good at getting her to her activities on time. She's had to give up on so many activities. So I wouldn't want to sign her up to something that we then can't fulfil. It's real shame. I think she has loads to offer.'

This problem is noted by other researchers, who cite non-attendance due to ‘transport difficulties, unavailability of helpers and work or other planned activities [receiving] a priority’²⁷.

3.5 Interviews with people with learning disabilities

3.5.1 The use of interviews with people with learning disabilities

Conducting one to one interviews is one of the most commonly used methods for accessing participants’ views, opinions and experiences. Many people with learning disabilities have receptive and expressive language difficulties, and this remains the most prohibitive aspect of their participation in research, particularly research that involves answering questions. There are obvious challenges if interviewees have difficulties in understanding or correctly interpreting the questions and coping with the interview’s requirements.

Researchers must be aware of threats to the reliability and validity of data that are present because of the participants’ learning disabilities. These include the inclination to answer questions with a single word or short sentence rather than a free-flowing conversation, requiring a higher level of input from the researcher²⁸; the tendency to answer ‘yes’ regardless of the question, and the tendency to select the last option^{29;30}; and problems with questions about time and frequency³¹. Some researchers have described interview techniques that are less reliant on words, such as the use of Talking Mats³² or pictures, stories and scenarios³³.

We found that unless the participant has a reasonably high level of verbal skill, simply asking questions is not enough: additional research techniques are needed in order to elicit the necessary data, which presents analytical challenges. It is not surprising that most studies with people with learning disabilities involve participants with mild to moderate learning disabilities who have a degree of verbal ability, and many authors acknowledge this limitation. This study is no exception.

3.5.2 The interviews in this study

The interview guide for one to one interviews can be found in Appendix 9.6. Two of the interviewees coped well with the interview questions and did not need any additional research techniques. Following the initial questions, one interviewee was shown a picture book about a woman receiving a cancer diagnosis and undergoing treatments, which helped to elicit further comments. One interviewee found it more difficult to understand the questions, and misinterpreted them at times. For example, all questions around ‘what was it like when X had cancer’ were answered as if Irene had asked ‘what was it like when X died’. This interviewee was shown the pictures of ‘Jim’s story’ (see Appendix 9.7, and section 3.6.4: focus groups session 2). All interviews lasted approximately one hour.

3.6 Focus groups with people with learning disabilities

3.6.1 The use of focus groups with people with learning disabilities

Of all methodologies involving participants with learning disabilities, the use of focus groups has perhaps been most extensively reported³⁴⁻⁴². A focus group is likely to be appropriate if the purpose is to explore the views, feelings and experiences of a homogenous group. It is less suitable if the researcher wishes to gather facts or to generalise the findings to a population⁴³.

There are a number of considerations for selecting a focus group methodology over individual interviews with participants with learning disabilities. Focus groups may be less daunting to participants, who may be unlikely to ‘open up’ to someone with whom they are not already familiar. Participants usually feel relatively empowered and supported by the group dynamic and are often willing to share feelings and insights in the presence of people they perceive as being like them in some way. The synergistic effect of the group may result in the production of data and ideas that might not have emerged in individual interviews⁴¹. We have found that whilst in the general population one to one interviews are more appropriate if the purpose is to gather data about personal experiences (including data on sensitive topics), the opposite may be true for participants with learning disabilities. The

presence of other group members, who may have similar experiences, can facilitate rather than prohibit the disclosure of personal stories.

In case of a sensitive topic with vulnerable groups, the distinction between a focus group and a therapy group can become blurred, with participants revealing painful personal experiences. At times, our focus groups seemed like a bereavement support group. The participants in one group expressed how beneficial it had been to them to be in a group with others who had been similarly bereaved of a relative or friend with cancer, and chose to keep meeting again without us after the research had finished.

The ideal group size depends to some extent on the complexity and sensitivity of the research topic. Although focus groups typically contain between six and 12 participants, with some researchers aiming for up to 20⁴⁴, we agree with Fraser and Fraser³⁷ that smaller groups are needed for participants with learning disabilities, and that between three and five groups lead to gaining the diversity of views towards saturation. We found that the most fruitful number of participants with learning disabilities per group is between four and six. This number allows for individual attention whilst still benefiting from the group process. We aimed to invite six participants to each group, so that if there was non-attendance from one or two participants, there would still be sufficient participants to allow for fruitful group processes to occur.

3.6.2 The focus groups in this study

There were two focus groups of six and one of five participants. Each group met four times for an hour at intervals that suited the group. The first group met at monthly intervals, as the participants travelled from all over London once a month to meet together, and our study fitted into these well-established meetings. The other groups met weekly, which was in fact preferable, as there was a certain momentum to the meetings. Meetings were conducted in a large room at day- and community centres.

Between one and five support staff who knew the participants were present at the meetings; their task was to facilitate communication and provide support during and after the meetings as needed, rather than to contribute themselves. This was hugely beneficial, as we didn't

know enough about the participants to judge when they needed additional support or when they could be left alone. We also needed to focus on the whole group, whereas a support worker could accompany a participant who wanted to leave the room (as several did during the course of the sessions – although they always chose to come back). However, there were also some drawbacks to having supporters present, which are described in section 5.

Amanda's support worker attended several sessions as well, partly because Amanda needed support with travel, and partly because it enabled the support worker to discuss Amanda's work with her afterwards, which was helpful.

Participants were paid £15 in cash at the end of each session, plus an extra £20 if they attended all four sessions, totalling a maximum of £80 for taking part. This is in line with national best practice¹⁶. The monetary recognition of participants' time and effort was clearly important and empowering to them. Many expressed delight at being able to contribute to what they saw as an important study, and receiving payment seemed to give the intended message that their contributions were highly valued.

3.6.3 Preparing for running the focus groups

We prepared for the focus groups during a number of team meetings. Irene had attended a two day training course on facilitating focus groups, and was keen to share her insights with the rest of the team. As three of the researchers (Irene, Gary and Amanda) were planning to co-facilitate the groups, we practised running mini-focus-groups with the team, where each researcher took turns to facilitate a short session. The focus of this training was on learning to withhold our personal opinions and experiences, as well as inviting all group members to have their say. However, as we will describe in the discussion (Section 5), this training proved to be largely irrelevant. In practice we found Gary and Amanda needed to employ facilitating skills that were quite different from Irene's.

We also prepared the structure of the focus groups, planned the story-telling we were going to use, and practised role play. Preparing for the role playing involved having several scenarios 'up our sleeve'. We didn't know how willing or able the participants would be to join in with the role play, so we prepared for several possibilities, ranging from sitting back

and letting the participants act, to Gary and Amanda taking on various parts. They excelled at this, as both had a background in acting professionally.

Immediately after each focus group meeting, the research team held a debriefing session, where we reflected on our experience of the meeting. The primary purpose of this was to provide peer supervision and to make sure we did not take the participants' experiences or feelings home with us. However, we found that these sessions contributed to the data analysis, and we recorded some of our observations as part of the data set.

3.6.4 The structure of the focus group sessions

Irene took the lead in facilitating the groups and was clearly regarded by the participants as the group leader. She introduced new topics and questions (or invited Gary or Amanda to ask these), ensured that all participants were able to contribute, decided when it was appropriate for Gary or Amanda to contribute their own experiences and opinions, and adjusted both the questions and the methodologies to the group dynamics and to people's communicative abilities. Gary and Amanda were instrumental in helping the group feel at ease. We found that rather than keeping their ideas, opinions and experiences to themselves (as the research text books insist and as we had practiced), the participants seemed more able to contribute when they saw Amanda and Gary contribute as well. As such, Gary and Amanda acted as 'role models' for the group. They also had an encouraging role as they responded with warmth and understanding to the participants' contributions. They had some specific tasks, for example, leading the start of the group, taking part in role play, handing out information sheets, consent forms and money. Such seemingly minor tasks did, in fact, serve a powerful purpose; several support staff told us afterwards how amazed the group members had been to see other people with learning disabilities work with us as colleagues.

Starting and ending the focus group meetings

Each focus group meeting started with the same 'ice breaker', a game for learning each other's names. This was led by Gary or Amanda. It was useful for four reasons:

1. It showed participants right from the start that Gary and Amanda were part of the research team.

2. It gave participants confidence. Most seemed a bit worried at first about whether they would be ‘good enough’ to take part in a group, and whether they would be saying the right things. Seeing that they were sometimes better at doing the ‘name game’ than we were (we took longer to learn everyone’s names!) helped them to relax.
3. Starting in the same way each time gave participants a sense of security and reminded them of the previous meetings, making it easier to get the rest of the meeting going.
4. It really did break the ice!

It was also important that during the last meeting, we did not explore any issues in depth, but rather re-capped on the experiences, ideas and opinions that had emerged; and we ended the meeting with a light-hearted celebration of the group’s achievement, for which we brought along food and drink. This echoes the structure of a “one-off” focus group meeting with participants without learning disabilities, where the last part of the meeting is spent disengaging from the topic and the group. We took some time to talk about what it was like to be in the group (see Section 4.8). As Amanda said:

‘We had a laugh, which was important because we wanted it to be fun as well. We didn’t want people to leave feeling sad. It was a way of saying goodbye to the group.’

Meeting 1

- Watching the DVD again that explained the study (see Appendix 9.4).
- Irene explained what we will do in the different meetings.
- Getting to know each other. Each person was invited to say something about their own experiences with cancer, or about their relative or friend. This was not a ‘round robin’: participants could contribute if and when they liked. All groups were helped in their ability to contribute by listening to Amanda tell her cancer story.
- We found that participants rarely explored their experiences and ideas in depth during the first meeting. This meeting enabled us to gauge the abilities and needs of each group, and adjust subsequent sessions accordingly.

Meeting 2

- We showed slides with drawings of a fictional story of ‘Jim’ whose father is taken ill and goes into hospital. His mother is crying because she is told that the father has cancer. Jim looks sad and worried (see Appendix 9.7)

- There were no words with the slides. We asked the group to tell us what they thought was happening in each picture.
- We asked the group: ‘What is Jim worried about?’ and ‘What would help Jim?’
- The story-telling worked very well for each group, with several participants commenting afterwards how much they enjoyed it.

Meeting 3

- Flexible. Each group had different needs and wishes.
- Group A talked some more about their own experiences, and were now more able to do this.
- Group B wanted Irene to explain facts about cancer. She prepared a slide show for this, spending some of the meeting talking about cancer and answering questions. This led to further discussion of cancer, personal experiences and questions.
- Group C wanted more pictures and stories to think about. We presented them with the nine pictures of ‘What would help’ (see Meeting 4) and discussed these together. We also included some ad hoc role play (see Appendix 9.9).

Meeting 4

- Based on the earlier meetings, we prepared nine cards with pictures, showing the different things that participants had said would help them (see Appendix 9.8). We were able to use the same cards with all groups, despite group C meeting almost a year after Group A; Group C had not generated any new ideas or suggestions.
- Each participant was asked to select the five ‘top ideas’ in order of preference, and put them in voting boxes (adapted ‘Nominal Group Technique’, see below). We ended the group with a celebration.

Nominal Group Technique

The Nominal Group Technique (NGT) was initially developed by Delbecq et al⁴⁵ as an organisational planning tool. The method was pioneered for use in research on sensitive topics with people with learning disabilities by Irene in a previous study¹⁴. Nominal group technique combines quantitative and qualitative data collection in small groups of stakeholders and typically involves four steps:

1. silent generation of ideas by each individual
2. round-robin recording of ideas
3. structured and time-limited discussion of ideas

4. selection and ranking of ideas (‘voting’)⁴⁶.

It is a single-questions technique, and its success depends on the unambiguity of a question that can generate a wide range of answers.

In our study, the question was: ‘What would help people with learning disabilities who have a relative or friend with cancer?’ The first step was not used in the textbook way; we had gathered the ideas during the first three meetings, and added further ideas generated during some of the one-to-one interviews. Steps two and three were eliminated, although we found that the discussion of the ideas with Group C during the third session was beneficial and helped their ‘voting’. For the selection and ranking, each participant was given a set of nine picture cards and asked to put these in boxes specifically designed for use with people with learning disabilities: from the largest box for their first preference (giving the idea 5 points) to the smallest (giving the idea 1 point). See Figure 1.



Figure 1: Gary demonstrates using the voting boxes

‘Counting the votes’ was done with the enthusiastic help of the participants, where the cards were taken out of the boxes and the scores counted (for example, in a group of six participants, the maximum score for an idea was 30 points – if everyone selected it as their first preference, giving it 5 points each). See Figure 2.



Figure 2: Counting the votes (photo taken during a previous study)

3.7 Data analysis

3.7.1 Summary of the analytic process

Each meeting was audio recorded and transcribed verbatim by a professional transcriber and then verified by Niki and Irene. Notes and reflections of the researchers were added at this stage and formed part of the data set; this included some of the comments from Gary and Amanda made during the debriefing sessions. Data were analysed using thematic content analysis. Throughout the study, the research team held discussions about emerging themes. The data were initially analysed by Niki and Irene, who developed a coding framework. After data collection ended, the full research team (including Gary and Amanda) was involved in the final analysis (see below). Initial findings were presented to the Research Advisory Group, who provided feedback. Data management was supported by Nvivo 8 for qualitative analysis⁶².

3.7.2 Involving researchers with learning disabilities in qualitative data analysis

Analysing qualitative data together with people with learning disabilities has only been described recently and very sporadically in the literature^{18;47}. We were guided somewhat by

these descriptions and our own limited past experience, but we had to be guided as much by our own ideas and instincts about what might work. Irene explained the analytical task as follows:

‘We have had 12 hours of meetings with people with learning disabilities, and they told us lots and lots of things. If we have just 15 minutes to tell others what we found, what will we say? What is at the heart of the groups’ experiences and opinions?’

The team held six meetings over a period of three months. Meetings lasted between two and five hours, and were punctuated by plenty of coffee, biscuits and lunch. The meetings involved repeated discussions about coding, labelling and interpretation of the data. Niki presented extracts of the data, which we read out together. We then discussed what the extracts were about, and tried to reach consensus about most appropriate theme for that extract.

During this process, we found that the data didn’t all fit neatly into the original coding framework. Gary and Amanda were instrumental in helping the team interpret some of the data and finding the right ‘label’ for it, or in offering an interpretation that was probably much closer to the participant’s experience than Niki and Irene’s. Here are two examples:

Niki and Irene had thought that one of the themes was the way in which participants were ‘excluded’ by their families, but Gary and Amanda disagreed. They suggested that rather than excluding them, the families were ‘protecting’ the participants. This did indeed fit better with the actual data.

We discussed the following quote: *‘I got a phone call from my dad saying, “hurry up and come home, cause I don’t think your mum has got long” and she died on Sunday night.’* Irene and Niki thought this was a positive experience, as the participants had been included in the family situation. However, Gary and Amanda could see nothing positive in it and commented that this quote was ‘really sad’. On reflection, we agreed that although it may have been worse for the participant if he hadn’t been at his mother’s bedside when she died, the overwhelming emotion this participant experienced in relation to his presence at his mother’s death was indeed one of profound sadness.

After five meetings, we finally found that we had got it right. We had four themes and a list of recommendations for how to support people with learning disabilities who have a family member or friend with cancer. We spent the last meeting on finding easy words and pictures to explain each theme and recommendation, so that we could feed it back to the participants. It was definitely a moment for cheers and chocolate cake!



Figure 3: Analysing the data together

3.8 Ethical aspects

There were complex ethical issues associated with this project, in particular around the inclusion of a highly vulnerable group in researching a sensitive topic. Due regard was given to all ethical issues.

3.8.1 Ethical approval

Ethical approval for the study was obtained from the national NHS Research Ethics Committee, using the online IRAS centralised system (reference 09/H0716/37). The study was adopted into the NIHR CRN Portfolio (reference 22142). R&D Trust approval was only needed (and obtained) for one of the focus groups, as all other participants were recruited through non-NHS routes.

3.8.2 Recruitment and informed consent

We followed careful recruitment procedures, to ensure that potential participants were not put under pressure to participate. This is particularly important for participants with learning disabilities, where the power imbalance between researcher and participants is greater than usual. Extensive consent procedures were part of this. These are described in detail in section 3.4.

3.8.3 Support for participants

We were aware of the potentially distressing nature of the research topic, and had anticipated including the presence of a therapist in the groups whose role it would be to focus on the emotional support needs of the participants. However, in all three groups, the professional co-ordinating the groups felt that this was not necessary. They felt that they themselves would be able to monitor the emotional well-being of the participants and inform us if they thought anyone needed additional support. This is indeed what happened; no such additional support was needed. We checked with the co-ordinator before and after each group that all participants were coping well with the study. In addition, all participants were given Irene's full contact details, and told that they could (and should) speak to either her or anyone in

their own support system if they felt they needed extra help. We had to consider the ethical dilemma of participants' personal cost of disclosure, as there were limited opportunities for us to follow up participants after the group; however, in practice we were confident that through the co-ordinators, participants were well supported after the focus groups.

In the case of face-to-face interviews, Irene made a follow-up phone call afterwards, either with the participants, or with their carer, or both.

3.8.4 Support for the researchers

Work of this nature can be emotionally demanding for the researchers. It is our experience that without adequate support, research of this nature can be difficult or even damaging to the mental health of the researcher. We had a number of support measures in place.

- We held a debriefing session after each focus group, where we talked through what had happened and how we felt about it.
- Irene provided one to one support by talking with team members on an as-needed basis. Irene has experience and skill in working with vulnerable people in research, including people with learning disabilities who are terminally ill and people with communication difficulties.
- Irene herself was supervised by Professor Baroness Sheila Hollins, who is a psychiatrist with extensive experience of supervising sensitive research projects.

3.8.5 Benefits

It is our experience in previous studies that, despite these potential risks, participants are usually keen to take part in such sensitive and emotionally demanding studies. This study was no exception. The benefits to research participants included:

- An opportunity to talk about difficult experiences with experienced and interested researchers, which was helpful and even therapeutic.
- An opportunity to share experiences with others in similar situations.
- An opportunity to learn something new.
- Participants felt empowered by the experience of being listened to, and the opportunity to help their peers through research.

- Participants derived meaning and comfort from the prospect of having their experiences published.

3.8.6 Disclosure, privacy and confidentiality

Researchers as well as members of the steering group are bound by rules of confidentiality. Data were handled and stored safely, accessible only to the researchers, according to the guidelines of St George's University. All names and some identifying details were changed to ensure anonymity. We were, however, aware of the fact that in qualitative research of this kind, there is always the possibility that a participant is recognised by someone reading the report, as some details of their published experience may be unique. Participants were made aware of this.

3.8.7 Research Advisory Group

The Research Advisory Group (see Appendix 9.1) acted as a safeguard. Part of their role was to monitor ethical issues and to be a sounding board for any ethical dilemmas encountered during the research. One of the members of the Research Advisory Group had extensive previous experience as a member of a local Research Ethics Committee.

4 Findings

4.1 The focus groups in practice

What kind of data emerged at each group, and how quickly or easily, depended on

1. Participants' intellectual ability, and their receptive and expressive verbal ability
2. Participants' experience of speaking and sharing in a group
3. Participants' combined experiences of cancer
4. Presence or absence of established group dynamics

4.1.1 Intellectual and verbal ability

Some groups found it easier to talk than others. The participants of group A and participant 14 (interviewee) had the most significant intellectual limitations and impairments in receptive and expressive verbal ability, with some using single words or very short sentences. In groups B and C the participants were able to respond to verbal questions with longer sentences. When we asked questions without using any augmented communication (such as adding pictures or signs), group A did not provide us with much data that could be meaningfully analysed. The group responded more easily to 'Jim's story' and to the adapted nominal group technique. In the description of the themes below, the participants in group A are quoted less often than those in group B and C; each of their verbal contributions tended to be short and less 'quotable'. The meaning we found was through having an overview of the whole meeting, for example, by recognising patterns in the nature of their responses, rather than finding meaning in a single response.

It could be difficult, even for us as an experienced research team working with people with learning disabilities, to keep our own language simple and to keep questions unambiguous. Participants tended to answer questions in the most literal way.

Participant 12: It's like your discussion now and I'm thinking, "you're talking all jargon" and I think "what is she talking about because I don't know?"

Irene: Did people talk to you in the hospital about things? [*meaning: explanations about cancer and the implications; offering emotional support*]

Participant 2: Yes. I couldn't find my way round the hospital to get there so somebody took me.

4.1.2 Experience of speaking and sharing in a group

Group B was by far the most experienced in talking about difficult issues in a group setting. This group was used to discussing possible themes for new drama performances about areas that affected their lives. They were strong and mature self-advocates (mean age: 51) who had learnt that they could have valid opinions that could be different from those of their families or carers. They were not afraid to speak their minds. The participants in group A were younger (mean age: 26) and appeared to be more dependent on their families, both practically and emotionally – it was perhaps significant that they all lived with parents (or an aunt), whereas none of the other participants did. They also seemed to be more concerned about 'getting it right' and pleasing the researchers, at least at the start of the process. Group C (mean age: 46) gained confidence as the meetings progressed. Participants in group C were not used to speaking in meetings, but responded positively to our encouragement and to Gary and Amanda's role modelling.

4.1.3 Experiences of cancer

The influence of shared experiences was particularly strong in group C, where participants were selected by the 'gate keeper' not simply because they had experienced cancer in their social circle, but because they were finding this aspect of their lives notably difficult. They were all grieving significant losses. The data collected in this group were coloured by this. Parental loss can affect people with learning disabilities particularly strongly, as we will describe in the Section 5.

4.1.4 Group dynamics

Group B was made up of participants who knew each other well. This, combined with their confidence in speaking out, meant that they were able to discuss difficult issues in depth

right from the start. However, we sometimes wondered whether established group dynamics prohibited full disclosure. Group C was the only group where participants did not know each other. This affected them, particularly at the first meeting, when they were brief in their responses and seemed to ‘test’ the group as well as the research team. However, once they began to feel secure, this group was able to speak freely; the presence of relative strangers who were nonetheless sympathetic and who had experiences in common seemed to help them disclose their feelings in depth. Reflecting on this, Gary said: ‘It’s better if they don’t know each other because you get an honest opinion. If you know each other, sometimes you just agree with each other.’ Amanda said: ‘If they do know each other, they don’t always open up.’

4.2 Overview of the findings

Four themes emerged:

1. **Protection and inclusion.** Participants who had not been told about the patient’s illness felt excluded. Being told that someone had cancer did not necessarily mean that the participant had understood the implications.
2. **Coping with cancer.** Participants had vivid memories of events and feelings. They worried about their families. Several had become carers themselves.
3. **Understanding cancer.** Participants lacked knowledge about cancer and wanted to know more. Many were worried that they themselves would get cancer.
4. **Someone to talk to.** Participants would have liked to share their feelings and questions with family, friends or professionals, but most had not done so.

Nine possible helpful support measures were suggested by participants during the course of the study. These were voted on by the 17 focus group participants. ‘Someone to talk to about my feelings and worries’ and ‘Someone to support the rest of my family’ emerged as the most helpful support strategies.

4.3 Protection and inclusion

When presented with the story of ‘Jim’, which left it open whether or not he had been told about his father’s cancer (see Appendix 9.7), participants answered to the question what was worrying Jim: ‘Nobody’s told him’.

Participant 8 [*reading the caption on the slide*: “What is difficult for Jim?”

(...)

Participant 9: No-one told him, yeah. That his dad is dying.

Irene: I don’t know whether Jim knows [*that his dad has cancer*].

Participant 17: No, he doesn’t know, does he.

Several participants speaking at once: No, he doesn’t know.

Irene: Why do you think he doesn’t know?

Participant 21: Because he hasn’t been told.

Participant 17 (*speaking with passion*): He hasn’t been told, has he!

Irene: Has he not?

Participant 19: I don’t think so.

Irene: Why not?

Several participants speaking at once: The nurses haven’t told him, mum hasn’t told him.

Irene: Mum hasn’t told him you said?

Participant 17: Don’t think so. I don’t know.

Participant 18: I can agree.

Irene: You think mum hasn’t told him?

Participant 18: Yeah.

Irene: And the nurses haven’t told him either?

Several participants speaking at once: No.

Participant 17: It’s against – they can’t tell him.

Participant 21: And he’d probably be upset as well, wouldn’t he?

Irene: So the nurses and the doctor have told mum, but they haven’t told Jim yet?

Participant 17: It’s up to the mother.

Irene: It’s down to mum to tell Jim?

Participant 17: Yes.

Irene: What do you think, should mum tell Jim?

Participants 17, 18 and 21: Yes.

Irene: Why?

Participant 19: So he knows and so he's prepared.

Participant 18: So he knows what's going to happen and how he's going to cope. I'm not blaming anyone.

Irene: We're not blaming anyone either, we're just wondering what's happened here.

Participant 18: Oh, that's good.

(...)

Participant 17: He must think something is going on but nobody is telling him properly (...) He can sense something's not right.

Participants talked repeatedly about whether or not they had received timely information from their families about the ill or dying person, and how they had felt (and still felt) about this. Several families seemed to not have shared information with participants as a way of protecting them from the bad news. Two participants described vividly how they were physically excluded from the rest of the family, causing distress and anger that had persisted for many years.

Participant 12: When my mum died, because I was so young, I was put in the kitchen and not told. So it was like, "what's happening, what's going on? I've got the right to be in here like anybody else." But they didn't want me with them. I was put in the kitchen and not told.

Irene: Why do you think that they put you in the kitchen and not tell you?

Participant 12: Because they, 'cause I was, because I had learning disabilities it was just like, "she don't need to know."

Irene: And why does somebody with learning disabilities not need to know do you think?

Participant 12: Because they're probably looking after me, they're making sure that my care, not worry or and anything like that. OK. They probably done right but it's just –

Irene: And do you think they were right not to tell you?

Participant 12: No. I don't think they were right. Why should they keep it from me?

Participant 11: I didn't know anything about it at all, with my mum or my sisters. It's like talking about it and I didn't know anything. They put me in a room and I didn't hear about it, I didn't know about it. It's not nice. I didn't know people get locked in a room you know. It's frightening.

Irene: If Jim doesn't know that his dad has got cancer, what is difficult for him?

Participant 18: To take it in, like me. It was difficult for me 'cause I didn't know my mum had cancer straight away.

Irene: And what was difficult about that?

Participant 18: Trying to understand why she became ill so suddenly (...) I didn't know to be honest.

Participants agreed that they had the right to know like the rest of their family members. Not all participants were able to indicate whether or not they had been told about the cancer at the time. Most seemed to have been aware of the diagnosis, but being told someone has cancer does not necessarily mean that all the implications are understood.

Participant 1: I just wish I was more prepared but I wasn't. I knew – it only dawned on me after when she was dead that the cancer killed her.'

Participant 12: I knew it was dangerous but I didn't realise what it was. They told me that they had cancer but what is cancer?

Participant 21: I didn't know how ill Q [*friend*] was until I had a phone call from his sister. She rang me up and said that oh Q's died.

Irene: But you didn't know before that happened how ill Q was?

Participant 21: Well I did know 'cause I was his carer. But I didn't want to give myself so much worry.

Others had a different experience:

Participant 10: The nurses explained it to me. About the cancer. Explained it to me.

Irene: Did you have to ask them or did they come to you to explain?

Participant 10: No no. They just came to me and told us. I'm the next of kin so they had to make sure I understood.

Being fully included could not, however, protect the participant from deep distress. Some participants' families not only spoke about the cancer diagnosis with the participant, but also included him or her in the situation.

Participant 20: I got a phone call from my dad saying, "hurry up and come home, cause I don't think your mum has got long" and she died on Sunday night.

Participant 18: Same as me.

Irene: Were you glad your dad rang you?

Participant 20: Yeah.

Participant 14 had been included by both her family and the hospice staff at the time of her uncle's death. This experience was crucial in helping her to understand and make sense of the situation, however hard it was.

Participant 14: My cousin arrived at the hospice. She was coming up there. She just came up.

Mother (*present at the interview to help with communication*): And then, when it was the right time, the nurse asked you if you wanted to go and see [uncle].

Participant 14: She asked me if I wanted to go and see [uncle].

Irene: Oh right. And what did you say?

Participant 14: I said to her yes. So I burst out cry – and then X [*my social worker*] was there when I came out.

Mother: You went in and sat with him, didn't you.

Participant 14: Yeah, and X was outside when I came out.

Mother: And what did you do when you went to see [uncle], when he had died, and he was lying in a bed, didn't he? [*Participant 14 nods*] What did you do when you were by yourself with [uncle]?

Participant 14: That I loved him.

Irene: You told him that?

Participant 14: Yeah. That I loved him very much.

Irene: That's a nice thing to say to him.

Mother: Yeah – and I think you gave him a kiss, didn't you?

Participant 14: I gave him a kiss.

Mother: Didn't you say, when you went in and first saw him, you said, "he's dead".
First of all you said, "wake up".

Participant 14: I said, "wake up". I said, "wake up. He's dead."

Irene: It's hard, isn't it. People don't wake up when they're dead.

Participant 14: It's hard.

These participants remembered the situation with feeling, but even though the memories of the ill person dying were painful to discuss, the issue was focused on missing that person and on trying to continue living without them.

4.4 Coping with cancer

4.4.1 Vivid memories

Many participants had vivid memories of their loved one being ill and dying, recalling the details even years later. The events related by participant 12, quoted above (about being put in the kitchen and not told about the cancer) had happened more than three decades earlier. She even remembered what the weather had been like. Participants recalled in detail the experience of coping with someone who was ill and watching them die, which had involved feelings of worry and general distress that still affected them today.

Participant 18: Me and my family witnessed my mum dying and that was *shocking!* She had a tumour, cancer in her brain. And she went to hospital thinking they could help her but... she came back home and that was sad. It was hard. I still cry sometimes 'cause it hurts. I do miss her. It was six years ago and it's still taking time to get used to.

Participant 1: Watching him die was awful.

Participant 15: I opened his bedroom door and his bedroom door was there and he was just lying there like he was fast asleep but he was dead.

It seemed that for many people with learning disabilities, the intensity and vividness of memories and continued emotions was not necessarily related to the time that had passed since the experience, but to the intensity of the experience.

It was particularly striking that the way many participants recalled events and made sense of them (especially, but not exclusively, participants in Group A) was not so much through discussing their emotions or the meaning of the events, but simply through recalling what had happened. Many participants returned to the same events again and again during the course of the interview or focus group meetings. The visits to hospital, the treatments, the death, the funeral. These events were out of the ordinary; they had stuck in participants' minds; they were life changing events that had to be assimilated. Simply recounting events seemed an important way of coping with what happened.

Participant 2: *[Addressing the husband, who was recovering from cancer]* You had to go by ambulance. They took you there. *[Addressing Irene]* I went with him. You didn't have to pay for that. And they gave him tablets (...) She *[support worker]* came to pick me up and then we went back to the hospital to pick him up. He was a bit wobbly so we put him in a wheelchair to take him down to the car, and then the nurse came to take the wheelchair, and he held my arm to the car because he was a bit wobbly. And then I sent him, he had to go to bed early.

Participant 3: He had a very weak voice, couldn't speak, and he had tubes in him and we visited when I, when we visited him – when I went in there – I didn't like to see him like that and it made me scared and made me upset. I didn't want him to go 'cause he was my granddad. And I didn't want him, I didn't want him to die.

The following extracts, recounting the events at the time of the participant uncle's death in a hospice, happened during the course of a one hour interview:

Participant 14

‘He had cancer. Then me and [*cousin*] had to go to the cemetery to bury him. That’s what happened.’

‘The nurse come and get me. He died at five o’clock in the morning.’

‘She came up and got me. Came up and got X [*a very supportive social worker, who had accompanied the participant to the hospice when the uncle died*]. She was talking to X most of the time. She wasn’t talking to me, she was talking to X. X knew. She come with me to the hospice.’

‘It was one of the nurses that come and got me.’

‘X was there as well. Telling me that [*uncle*] died at five o’clock in the morning.’

‘One of the nurses told me. Just before he died.’

This participant was not able to answer questions about the earlier stages of the uncle’s illness, as the experience of his death was so overwhelming:

Irene: What was the first time when you thought that [*uncle*] was ill?

Participant 14: I just found out.

Irene: How did you find out that he had cancer?

Participant 14: The nurses told me. She come and got me from upstairs.

Irene: Ah, that was after. When you heard that he had died.

Participant 14: Yeah. They took him to cemetery to bury him. All relatives came.

4.4.2 People with learning disabilities as carers

In many cases, as the cancer progressed and the cancer patient needed more assistance in daily tasks, the role of participants changed. Seven participants indicated that they had gone from being cared for or being an equal partner to being the carer of their relative, partner or friend. Many participants ‘got on’ with it and took on their new roles as carers, even though this was distressing for them.

Participant 1: She [*mum*] was having this drip or whatever [*note: chemotherapy*]. I used to help her with the house because it used to tire her out. It used to. (...)

Because mum had already gone and it was just me and dad living at home, with dad I was like his carer. I had to do everything for him (...) He used to like cook dinner for me, do the housework (...) My mum died in *[month and year]*, my dad died *[17 months later]*. It wasn't long at all and I had, and I even had to help him get his clothes on, it was embarrassing. I hated it. I didn't get paid for it either like you can nowadays to be cared for. It's awful.

Participant 2: I was looking after him *[husband]* (...) He was my patient and I was a nurse!

Participant 15: My friend was kind of like a partner to me and then I was his carer in the end (...) He was carer for me when I first met him and then reversed roles. I was very close to him. I used to just support him if he needed lifting.

Participant 9: I looked after my mum at home (...) Difficult, it was. I was looking after her 24 hours a day. On the commode and that. She used to sleep upstairs, she used to call me.

Participant 19: My partner had cancer and he died last year. I was his carer.

The carer's role was a worrying one. Participant 13, who was the only participant still in that carer's position at the time of the study, explained:

Participant 13: I am just worrying about him now. It's like this morning, I got up, he called me, I got up and I said to him, "how do you feel now?" So he says, "oh, I'm not well". I thought, "oh no". He keeps on and on and on, and I think, "oh no". I thought, "what can I do?"

Participants viewed themselves as able to understand, help and to be responsible, but they seemed to have received little credit or support for this.

Participant 15: I think it upset me that the doctor didn't actually believe that he was ill. I just felt really cross that she didn't bother to – maybe she should have asked me

what he was like before. And I knew that he wasn't putting it on (...) I really felt cross that nobody actually listened to me.

4.4.3 Worries that the cancer patient is going to die

Irene: If somebody you know, like your family or your friend, has cancer – what is it that is difficult? What makes it difficult?

Participant 8: It's they worry that they could die.

Irene: The worry that they could die?

Participant 8: Your heart stops. [*inaudible, as he stamps his feet very loudly*] I did stamp my feet! We all cried.

Participant's overwhelming concern that the cancer patient might die was deduced mostly from their responses to our question 'What do you think Jim is worried about?' in 'Jim's story' – although some of these answers may have stemmed from the fact that they now knew more than 'Jim'. They had experienced the death of someone close to them, and realised that the very ill father in 'Jim's story' could die (although this was not made explicit in the story: we simply told the participants that Jim's father had cancer).

Irene: I don't know what Jim is thinking. What is he thinking? What do you think?

Participant 14: He thinks he's gonna die. Yeah (...) He is worried, I think.

Irene: What do you think he might be worried about?

Participant 14: He can't talk to him. He thinks he's going to die in the hospice. In that bed. Like [*my uncle*].

Participant 15: He's probably worrying about if he's going to ever see him again. Because he's very fond of his father.

Irene: What might be difficult for Jim?

Participant 6: Losing his dad.

Irene: Losing his dad? Do you think Jim is worrying about that?

Participant 6: Yeah. [*pause*]

Participant 3: Maybe he doesn't want his dad to be dead.

Irene: If you imagine that Jim has been told everything that's going on, what do you think is difficult for him now?

Participant 20: I'll be left on my own, being left on his own day in and day out without him.

4.4.4 Worries about the family

Participants were acutely aware of the distress and needs of their families. This concern was expressed by one participant who thought 'Jim' would be worried about his changing responsibilities:

Participant 9: Jim would have to look after the family, wouldn't he?

Irene: You think he might have to look after the family?

Participants 9 and 10: Yeah.

Participant 9: If his dad passed away, he would have to look after the family, wouldn't he. He is the man of the house.

Other participants agreed.

Participant 11: The thing is, you've got to be responsible in the family.

One participant expanded:

Participant 18: I've seen my dad with tears in his eyes. That isn't easy, to see that. *[Several participants are nodding. Irene asks the group whether they would like to act out 'Jim' talking to his family. The group is keen on this, and decides that the role-play should include Jim and his mother. Gary role-plays the mother; participant 18 volunteers to play Jim]*

Participant 18 (addressing 'mother'): I'm fine but sad.

Gary: I'm worried about you and the family. It makes me sad.

Participant 18: Yes, I'm worried about you too.

4.4.5 Worries about getting cancer

Many of the participants expressed fear and anxiety about the possibility of getting cancer themselves. This is linked to the theme 'Understanding cancer' (see below), and may have been exacerbated by a lack of understanding of the causes of cancer.

Participant 1: You see, that's why I'm scared I'm going to get it because if my mum had it, my dad had it. Recently my mum's brother had it, he had throat cancer and he, and he, and he only had it for three months and then he died.

Participant 9: My mum had bowel cancer and I was worried I'd get it.

Irene: It worries you in case you get it?

Participant 12: Yeah coz when we get cancer, what's going to happen to us? I wake up every day thinking is it today that I get cancer? Is it tomorrow? Is it the next day? And you think 'don't be silly you're not going to get it!

4.4.6 Grieving

Most of the participant had been bereaved of someone very close to them. Nine participants had lost a parent through cancer. Much time was taken up with simply remembering what had happened, remembering the person who had died – this wasn't just a way of coping with cancer, it was a way of coping with loss and grief. Some participants had been supported in this, but many had not; their grief and sense of loss was raw, even many years later.

Irene: Does anyone else want to say more about what it was like for you?

Participant 8 [*mother died about a year ago*]: What else – what else – [*pause. Loudly, stamping feet*] MUMMY! I'm back now! Hello mummy! Hello mummy! Open the door: Hello mummy, I'm back now! I tell her I am back. That I am back home, when I open the door. I'm back now mummy! That's what I used to tell her every week, when I come back. I tell her. I open the door with my key. Hello mummy! I'm back!

Irene: Hmm. It's those kind of things that you miss, isn't it.

Participant 8: YES! Yes I do. I go still past the cemetery on the bus, past the cemetery and I talk to her. On the bus. Yes, I do. Talk to her. Yeah, I do.

Many participants had suffered multiple losses, not just through cancer. These other losses also surfaced when thinking about cancer. Participant 16, who had autism as well as learning disabilities, listed them all:

Participant 16: My mum died of pneumonia [*gives exact dates*]. I was 27 at the time. I'm 34 now. And I was very upset I was. I cried. But now time has gone on and I just smile and think of all the happy memories. And then my friend Y died [*four years later*]. My friend Y died of cancer as well. And I was very upset but now as time has gone on I think of the happy memories. And my brother Z died [*two years after Y's death*]. And my brother had cancer. So I've lost my mum, Y and my brother Z. So I've lost three people and it's still hard now. [*Group nodding in agreement*] (...) I was 31 when I lost Y and I was 33 when I lost my brother Z.

4.5 Understanding cancer

There was an overwhelming need for information about cancer from all participants. They had many questions highlighting the lack of information available to them. This was associated with anxiety – some participants had seen their relative die and wondered when they themselves would get cancer and also die, as described above.

4.5.1 What is cancer?

There was some confusion and a lack of understanding about what cancer was.

Irene: Let's imagine that Jim's mum and dad have sat down with him and his sister. And they've said, "now Jim, very sorry, but dad's got cancer". What do you think, if that has happened, what would be difficult for Jim?

Participant 11: He would be confused.

Irene: He would be confused?

Participant 8: Confused.

Irene: What would he be confused about do you think?

Participant 10: What does it exactly mean? And how will it affect the whole family?

Other participants were equally confused about what cancer is and how you would know that you had cancer.

Participant 1: Is it like a living, a living organism or a little, a little – like a little flea or something? (...) You see I don't know what sort of symptoms to look for if I had it. I've got nobody here to tell me, to explain it to me. So how am I meant to know? (...) You don't learn about cancer at school so how are you meant to know? (...) They do sex education so why can't they discuss about that?

Participant 12: You can have cancer like a monster, and draw it. Like a monster, and put arms and legs on it.

Irene: Does anyone know what cancer is?

Participant 5: Spots.

4.5.2 What causes cancer?

Participants wanted to know why someone gets cancer.

Participant 13: When I was married 16 years ago he never had it. It just appeared you know!

They made a clear link between cancer and known causes of some cancers, but had understood this in a rather black-and-white way: cancer always has a cause, and the cause always leads to cancer.

Participant 1: People who smoke always get cancer.

Irene: What is cancer?

Participant 12: Smoking. Pollution.

When Irene explained that there may not be a known cause for someone's cancer, participants found it hard to believe this. They thought that doctors should have the answer to everything.

Participant 20: If you're a doctor you should know!

Participant 17: They're experts, they should know!

Irene: 'If a doctor said "I don't know" what would you say?

Participant 20: I'd say, "What'd you go to medical school for?" Of course he should know! He's the doctor!

Appendix 9.9 gives an example of how using role-play helped one participant to express his worries and confusion about his mother's cancer and dying:

Participant 20: One day they are alright and then suddenly they're not. How does that happen?

4.5.3 Can you catch cancer?

There was general ignorance about cancer, with several participants asking whether you can catch cancer, to which other group members did not know the answer. In the following extract, there is further discussion about what might worry Jim in the story:

Participant 11: The thing is, it might infect his son. [*Irene misheard and understood "affect"*]

Irene: It might affect his son? Yes, that's a good point. In what way might it affect him?

Participant 11: It might spread everything around the whole family, who have cancer.

Irene: Oh right. So do you think Jim would be worried that he would catch the cancer?

Participant 11: Yeah.

Participant 8: Yeah.

Gary: Well I don't know if cancer is catchable. I don't know that much, enough, to say it's infectious, if you know what I mean.

Irene: Oh right. *[to the group]* What do you think, do you think people can catch cancer?

Participant 10: He could be thinking about it, you know.

Irene: He could be worrying about that?

Several: Yeah.

4.5.4 Accessible information materials

Participants expressed the need for more information about cancer and proposed that this could include pictures to make it easier for both doctors and nurses to explain, and for people with learning disabilities to understand. As one participant proposed:

Participant 1: They should have it in easier words, easy format for people with learning disabilities to understand because how are they to know otherwise?

Participants greatly enjoyed looking at the pictures we used from 'Books Beyond Words', or (in the case of some interviewees) at the entire book. They linked the pictures to their own experiences, and it prompted them to talk about it.

Participant 2: Nice to get something like this *[picture book]* – it might help, you know. (...) *[looking through the book's pages]* And that's her in bed. She looks really ill, doesn't she, there. Get better! That's her mum (...) Look, she looks worried there and she – this is a good book!

Participant 12 *(talking about the pictures in 'Jim's story')*: You can see there, Irene, the boy is sad. Because he doesn't know. I didn't know that my mum died of cancer. I wasn't told.

In the following extract, Irene shows the pictures of 'Jim's story' to participant 14, whose uncle had died in a hospice.

Irene: That's his dad – or do you think it is his uncle?

Participant 14: It is his uncle (...)

Irene: I don't know if it's a hospital or a hospice...

Participant 14: It's a hospice. Because look... *[turning to the picture of dad in bed]*

Yeah! That was it! He had a drip – yes, I recognise the hospice. Just round the corner from me.

Irene: So Jim's uncle is in the same hospice, do you think?

Participant 14: Yeah, he is in *[name of hospice where her uncle died]*

4.6 Someone to talk to

The majority of participants found it helpful to talk with someone, whether it was a friend, relative or professional. Most participants seemed to have few people to look to for support apart from their families, so it was the family that they would turn to first. Some had been able to ask their parents questions.

Irene: Did any of you have anyone to talk to? Did anybody have someone they could ask question about it?

Participant 9: My sister.

Participant 8: My mum told me all about cancer. She told me all about it.

Participant 7: I talk to my dad about it or my mum.

However, they also seemed to be protecting their families from their own distress, and many found that they could not actually ask their families for support. They also did not know how to approach professionals.

Participant 12 *(talking about 'Jim's story')*: Now that his dad's got cancer, no-one is there to give HIM support. He can't turn to his mum.

Irene: Why not?

Participant 12: Because his mum wants to be on her own (...) I'd be like that. I can't turn to my mum.

Participant 1: I can't go to my brother and his family. You must be joking. (...)

Irene: You didn't ever have a doctor or a nurse talking to you or explaining anything to you?

Participant 1: No, nothing.

Irene: Ever?

Participant 1: Nope. It was only when she went for chemotherapy, then I sort of overheard what the doctor said. So if my mum didn't tell me I wouldn't have known nothing (...) If there was support out there to say that you can get support while they're going through, but because nobody said anything.

Irene: What kind of support?

Participant 1: Well like emotional support to sort of help me to get through it.

Irene: What, someone to talk to?

Participant 1: Yes. It would have been a lot easier, not to go through it by yourself.

Participant 15: 'It was really difficult to talk to my parents. They didn't really like the relationship [*with the partner who had died of cancer*].'

Participant 17: My brother and my sister none of us talk about our mother, 'cause they find it hard so it never comes up (...) We never talk about our mother. I find that strange (...) Feel like you're putting your foot in it so I just keep it to myself.

Participant 18: It is hard to talk to the family 'cause I really don't know how they are going to react.

Participant 20: If anyone took it hard my dad did. I mean, he still does now. But he won't talk to me about nothing. I say, "talk to me – we got each other at the end of the day."

Participant 18: Yes, that's the same with me and my dad. (...) My family don't talk about it. I find it easier to talk to someone else. (...) It's not always easy to find someone. It's a good thing to talk about worries but if there is no one around it's difficult.

Irene: So it's good to talk to someone, but it can be very difficult to find someone to talk to? [*group makes sounds and gestures of agreement*] (...) How easy is it for you to go up to a nurse and ask them?

Participant 18: Ooohhh, I would have to be very brave. It would take a lot of courage.

Participant 20: I would do it because I'd have to.

Participant 17: They would understand...

Irene: What if a doctor or a nurse came to you and asked you "Is there anything you want to ask?"

Participant 18: I would like to, but without crying. And I'd be crying my eyes out.

Irene: Did any of you talk to a nurse? [*None of the six participants had done so*]

Family and support staff may not pick up that people with learning disabilities need emotional support. The support worker of participant 2, who was present in the house during the interview, said that she had failed to notice how distressed the participant had been when the husband was diagnosed with cancer and went into hospital; she had not linked the participant's withdrawn behaviour to distress.

Participant 2: I was crying when he went in. You know, I was crying. I really missed him. And I was very quiet, I was very quiet all those weeks when he was in hospital.

Participants who had been able to talk to someone had found this very helpful. Professional support, when given, was highly praised.

Participant 19: [*Partner*]'s parents were there and [*learning disability support workers*] were there as well and they helped me through.

Irene: How did they help you?

Participant 19: Chatting to me and helping me out, telling me everything that went on.

Participant 2: Just sitting there and talking to a nurse [*in the hospital*], that helped me.

Participant 14: ‘I can talk to [*support worker*]. One day I was up in my bedroom and I was really upset. And one of my support workers came up and talked to me.’

Participants thought it would be helpful to have someone to talk to, not only for emotional support, but also to answer questions.

Irene: What would help Jim?

Participant 10: Talking to someone that could answer his questions.

Irene: What sort of questions would he like to ask?

Participant 10: Can you catch it? You know? Would it affect [*OR: ‘infect’?*] him personally, and his children, things like that.

Irene: So, talking to someone who can answer your questions.

Severall: Yeah.

Irene: Who do you think that might be?

Participant 10: The doctor.

Participant 8: Or the nurse. At the hospital.

Irene: What would help Jim?

Participant 18: To be told and then comforted, helped through it.

Participant 16: It would help to be told and then comforted, yeah.

Participant 17: And if you’ve got anybody to talk to him and explain things.

Participant 21: If he’s got any relatives or anyone, friends could help.

Irene: Relatives or friends to help? What could his friends or relatives do to help him do you think?

Participant 17: Be there to talk.

Participant 21: Be there and comfort him if he needs anybody to look after him.

(...)

Irene: Rather than what would help Jim, if it was your own story, what do you think would have helped YOU?

Participant 17: I think somebody to be there to talk to me. I never got to know most of it, my mum’s funeral, that she wanted to be cremated, nobody told me. So really, I would have liked somebody to be there for me.

Irene: And would it be somebody in your family, or somebody from outside?

Participant 17: Somebody, hopefully family.

(...)

Participant 17: Support workers [*from learning disability services*] are actually brilliant. They listen to what you have to say.

Participant 20: The ones at [*name of learning disability organisation*] are idiots!

Two participants mentioned receiving counselling after their parent had died. Both participants found this to be a very positive experience.

Participant 15: The hospice was very good because they were very supportive. They have counselling which I thought was really great. And I think it really helps. I think I would never have got over all of it completely if I didn't have counselling.

4.7 What helps?

The participants suggested a wide range of strategies that they would have found helpful. During the last session, the focus group participants were presented with the nine most frequently mentioned strategies, using picture cards (see Appendix 9.9).

There were 16 voting participants (one focus group participant was absent during this session). They were individually supported to select their 'top five' and to put these in the voting boxes in order of preference. All were able to complete this task, mostly with great enthusiasm and pride.

Figure 4 gives the results of the voting. Each participant could give items a score between 0 (not selected in their top 5) and 5 (first choice).

- 'Total points' relates to the total score for that item, having added all participants' scores together. Thus, the maximum score for an item would be 80 (if all 16 participants had selected it as their top choice).
- 'Mean rating (all participants)' is the average rating for that item per participant, including those who did not select the item.

- ‘Mean rating among participants who selected this in their top 5’ is the average rating for only those participants who selected the item, and is therefore a more accurate indicator of how strongly those who selected the item felt about it.

Two items were selected in the top 5 by two thirds of the participants. Thirteen out of 16 participants selected ‘someone to support the rest of the family’ in their top five, giving weight to their expressed concern their families. Twelve participants selected ‘someone to talk to about my feelings and worries’; those who did ranked this item higher overall (six participants ranked it in their top 2), giving it the highest total score. This also reflects the content of the discussions during the focus group sessions.

‘My family, carers and doctor should tell me everything’ and ‘Someone I can ask questions about cancer’ was selected by just over half of the 16 participants, but those who did ranked it high. This could indicate that not everyone wanted to know everything about cancer and about what was happening, but those who did felt very strongly about it.

Observing the participants’ voting, it seemed that most were clear about which items they selected as their top one or two choices, but were then somewhat haphazard about their further choices. With this in mind, we have also noted in Figure 4 how often an item was ranked first or second. The most frequently selected items in the top 2 were:

- Someone to talk to about my feelings and worries
- A support worker to be with me
- Someone I can ask questions about cancer

This reflected the differences between groups (see below).

The following items featured only once or not at all in the top 2:

- Photos of the ill person to help me think and talk about them (*this item had been suggested by an interview participant; the groups were given the opportunity to consider it and vote on it*)
- Easy words and pictures to explain cancer (*this item was suggested in all groups, but did not receive the highest votes*)
- Someone to help look after the ill person

There were differences between the groups, and this reflected the discussions and needs in each group.

- **Group A** gave top scores to the following items:
 - A support worker to be with me (*participants in this group probably had the highest individual support needs, and were less independent than the participants in the other groups*)
 - My family, carers and doctor should tell me everything
- **Group B** gave top scores to the following items:
 - Someone I can ask questions about cancer (*this group requested a cancer information session*)
 - My family, carers and doctor should tell me everything
- **Group C** gave top scores to the following items:
 - Someone to talk to about my feelings and worries
 - Other people with learning disabilities to talk together about our experiences (*this group seemed like a bereavement support group, with participants very keen to share their experiences with each other*)

FIGURE 4: Helpful support strategies, suggested and voted for by the participants (n=16)

	Total points	Mean rating (all participants) (min: 0.00; max: 5.00)	Total number of participants who selected this in their top 5	Total number of participants who selected this in their top 2	Mean rating among participants who selected this in their top 5 (min: 1.00; max: 5.00)
• Someone to talk to about my feelings and worries	40	2.50	12	6	3.33
• Someone to support the rest of the family	35	2.19	13	3	2.69
• My family, carers and doctor should tell me everything	34	2.13	9	4	3.78
• Someone I can ask questions about cancer	32	2.00	9	5	3.56
• A support worker to be with me	31	1.94	10	6	3.10
• Other people with learning disabilities to talk together about our experiences	29	1.81	9	4	3.22
• Easy words and pictures to explain cancer	18	1.13	6	1	3.00
• Photos of the ill person to help me think and talk about them	10	0.63	6	0	1.67
• Someone to help look after the ill person	9	0.56	5	1	1.80

4.8 The experience of taking part in the study

At the end of the final focus group session, when asked what it had been like to take part of the study, participants' responses were overwhelmingly positive. Feedback from the managers and support staff was also very positive. They confirmed that after the focus group sessions, participants had remained very happy about the meetings. They were proud of being part of this study and being able to contribute. One participant described the meetings as 'great fun'.

Although it had been difficult and sometimes painful to talk about the issues raised, participants said they were glad they had done so. For many, it was the first time they had an opportunity to talk about cancer and how it had affected them. Group C exchanged phone numbers and kept meeting after the study ended; the group had become a source of mutual support.

Selected comments from focus group participants:

'We could talk about what we wanted.'

'It gave us an opportunity to talk about it. We don't usually get it.'

'I found it hard at first. The first meeting is always hard. Then it became easier.'

'It was upsetting sometimes. I used to cry my eyes out. But I still wanted to be in the group. It was good.'

'It is good to have somebody to listen to us. Not get pushed to one side.'

'It is good to talk.'

'It was not easy. After the first meeting, I thought about whether I should go back. But then I decided that I would. I'm glad I did.'

When asked what they had liked most, they mentioned the fictional stories, the voting, and the opportunity to share with others and find out that 'you're not the only one'.

Support staff expressed surprise at the depths of their clients' feelings and the ability of participants to express their experiences, with several staff commenting, 'I never knew that about him/her' – despite having known their client for many years.

The participants said that they found the presence of Gary and Amanda particularly helpful in enabling them to share their thoughts (see Section 5.5.4). Support staff were also full of praise for the impact of having Gary and Amanda in the group, calling it ‘inspirational’ and ‘empowering’ for their clients to see someone with learning disabilities in a position of authority and being listened to. They were particularly impressed that Amanda had turned her own experiences with cancer into something so positive. It made the participants feel that their story had value too. One learning disability community nurse said: ‘It makes the others think: maybe I can do that.’

5 Discussion of key findings

5.1 Information needs

5.1.1 The importance of accessible cancer information materials

We start our discussion with the lack of knowledge and understanding of many people with learning disabilities, as this is perhaps the most unsurprising finding, which has been noted before²⁰. People with learning disabilities often depend on others to enable them to access information. This means that other people have to:

- (a) recognise their information need,
- (b) wish to meet their need, and
- (c) know how to meet this, which includes finding accessible information.

There may be barriers in all these three areas. Knowledge of cancer is further limited by the lack of direct access (i.e. without the help of others) people with learning disabilities have to written information, news stories and stories shared with family/friends. In our previous research we found that both family members and paid care givers want to spare people with learning disabilities from distress. When they were uncertain whether the person could understand, they tended to withhold potentially upsetting information^{19;48}.

There is a clear need for easily accessible cancer information; without this, it is much more difficult for families, carers and professionals to help people with learning disabilities understand. This need is increasingly recognised⁴⁹, with a growing number of resources available, for example:

- **Books Beyond Words** is a series of picture books that has been developed to make communicating easier for these people with learning disabilities, and to enable discussion about difficult topics. The pictures are designed to help the reader make sense of what is happening to them, and help them to ask questions or share their concerns. Supporting text and guidelines are also provided for carers, supporters and professionals. We used pictures from these books in the focus groups and interviews. Useful titles include:

- ‘Getting on with cancer’ (about cancer diagnosis and treatment)
- ‘Am I going to die?’ (about end of life care)
- ‘When mum died’, ‘When dad died’, ‘When somebody dies’ (about bereavement and loss)
- **FAIR** (Family Advice and Information Resource) are an organisation who provide easy-to-read information for people with learning difficulties, including some booklets, CD roms and other materials on a range subjects including checking for cancers, living with cancer, bowel cancer and maintaining good health.
- **CHANGE** have produced six easy-read information books about cancer for people with learning disabilities and their carers, including “Diagnosis and treatment” and “Palliative care, end of life care and bereavement. The books have been made available free of charge by Macmillan Cancer Support.

See ‘Resources’ (Section 8) for details. Only the titles on bereavement have an explicit focus on the patient’s relatives and friends; there is currently a lack of resources aimed at supporting relatives during the patient’s illness (except some of the pictures in ‘When dad died’ and ‘When mum died’).

Our study found that showing people with learning disabilities just a few relevant pictures of situations that bore similarities to their own, and inviting them to voice their comments and questions, was a very effective way of eliciting concerns. This has implications beyond the research setting. Clinicians also have a remit to elicit questions and concerns, not only from people with learning disabilities who have cancer but also from cancer patients’ family and friends with learning disabilities. The pictorial resources could be used flexibly in a clinical setting, just as we used them in research.

5.1.2 The limitations of accessible cancer information materials

Despite the importance of having access to easy-read and pictorial cancer information materials, our study shows that they may not be the most important source of support for people with learning disabilities. When asked to select the most helpful support strategies, ‘easy words and pictures’ scored much less highly than strategies that involved ‘having someone to talk to’ or ‘someone to be with me’.

Let us consider again the above-mentioned important prerequisites for receiving adequate information – i.e. the need to have someone who recognises the information need; wishes to meet this need; and knows how to meet it, which includes finding accessible information. Our study found that the most important for people with learning disabilities is to have someone who can recognise their needs and is willing to meet those needs. The need for ‘someone’ outstripped the need for accessible information materials. The participants in this study wanted to have someone who could help answer questions, someone who could be a supportive presence, someone who was willing and able to include the person. Pictures and easy-read resources are only one part of this. They are a tool. A tool can be invaluable, but tools are only as good as the people using them. Outside this study (and this is our own anecdotal experience) we have seen practitioners use excellent pictorial information materials in a way that was counter-productive and hindered rather than facilitated communication.

If there is a ‘supporter’ (which might be a relative, a learning disability professional, a cancer/palliative care professional) who can recognise the person’s need and is willing to meet it, there are further possible barriers to meeting the information needs of people with learning disabilities. The supporter needs to be able to use the pictures and easy-read materials in an accessible way. They need to be able to answer the inevitable questions that the person may have; learning disability support staff may struggle with this⁴⁸. They themselves need to be able to use simple and straightforward language. This needs constant vigilance, bearing in mind that many people with learning disabilities, particularly those on the autistic spectrum, may take words literally. It must also be noted that information about cancer and all the changes that brings is necessarily complex. Understanding new and complex information is more difficult for people with learning disabilities – in fact, this difficulty is part of the definition of ‘learning disability’. Understanding abstract concepts (including concepts of time and future) can be particularly difficult. It is therefore inevitable that people with learning disabilities need extra support in this area.

5.2 The need for emotional support

The extent to which participants felt isolated and in need of emotional support was striking. This was not primarily a desire for straightforward cancer information, but for someone to share worries and concerns with.

5.2.1 Families could not provide sufficient support

Participants protected their families

Many people with learning disabilities have limited opportunities to build and maintain social networks and friendships^{51;52}, and therefore their support system consists primarily of their immediate family or care givers. However, at a time of crisis caused by cancer, when they most needed support, the people in this study were acutely aware of their families' distress. They were suffering in silence and seemed to have hid how they really felt, partly because they did not know how to approach others for support, and partly because they did not want to burden their families at a distressing time. When we analysed the data, Gary concluded that people protected their families by not asking 'a thousand and one questions because the family was too busy grieving'. Some participants suffered added feelings of rejection from what was their primary social support network, caused by a lack of inclusion, which seemed to have complicated their grieving process.

The mother who was present at the interview with participant 14 confirmed how difficult it had been to provide support to her adult daughter during the uncle's (her own brother's) illness and after his death:

'There was a dual thing going on all the time, because my needs were completely different from what [participant 14] needed.'

Participants did not receive support from professionals

Where can people go for support if they can't ask their family and they don't have anyone else? We found that the participants in this study did not ask professionals for support: they either didn't know such support could be asked for and given, or they were too hesitant to ask – as one participant said: 'I'd have to be very brave.'

People with learning disabilities are not unique in their need for emotional support when someone close to them has cancer: relatives in the general population have this need too^{53;54}. The participants' inability to receive support from their own families at such a distressing time may not be very different from patients' relatives in the general population. What sets relatives with learning disabilities apart is the extent to which professionals may assume that their family members are providing such support. Our previous study found that many health care professionals strongly rely on the carers of people with learning disabilities (often their families) to provide all support and information. This could stem from a lack of confidence in the professionals' own abilities to support someone with learning disabilities.

‘Health care staff were nervous and unsure about communicating with people with learning disabilities. They were unaware of specific communication characteristics (e.g. the tendency to agree with the questioner), or of the range of possible communication techniques.’¹⁹ (p. 163)

There were exceptions. Some participants had been offered counselling – but these were some of the most articulate participants who did not need communication to be augmented. Overall, our findings support the conclusion of the Independent Inquiry into access to health services for people with learning disabilities:

‘For the most part, innovation and good practice owed more to the enthusiasm of energetic individuals than to any structured and systematic engagement by health services.’⁵⁵ (p.9)

Someone to talk to, or a supportive presence?

The focus groups that were more articulate wanted someone to talk to and someone they could ask questions; the less articulate group wanted ‘someone to be with me’, a supportive presence. What these groups had in common is the need for someone to recognise their distress, to recognise that they were deeply affected by their loved one’s cancer and dying, and to be there for them. That could be through talking, through looking at pictures together, or simply through being present. Whilst we cannot generalise beyond these groups, and certainly not to people who are different in their (dis)abilities and levels of impairment, we

would like to speculate that having someone who is ‘there’ and present to the person is incredibly helpful and supportive to all people with learning disabilities. It may be suggested that this is helpful to anyone, whether they have learning disabilities or not; the difference is that people with learning disabilities may be much less able to express this need, ask for it, or simply have it recognised by others.

The findings of the first focus group meetings in each group are strengthened by the results of the voting during the final meeting. All three groups selected strategies that reflected their need to be supported. Their voting also demonstrated a need to be included (‘Tell me everything’). They wanted to have their fears and worries recognised and find support for them, including worries about their families. The manner in which such support is given will depend partly on the person’s level of intellectual and verbal capacity (some people may wish to talk about their feelings; others may simply wish to have someone sitting with them or helping them to visit the patient).

5.3 People with learning disabilities as carers

The needs of family caregivers of cancer patients are increasingly recognised; a recent literature review found 164 research-based articles about the types of problems and burdens such caregivers experience⁵⁶. However, people with learning disabilities who are carers are often invisible to services because of lack of recognition of mutual caring of parents or partners⁵⁷.

We were struck by the number of participants who became, or certainly saw themselves to have become, carers; but on reflection, this is not so surprising. Growing numbers of people with learning disabilities are still living at home with family carers who are aged 70 or older. As family carers start needing more support themselves, the families develop routines and ways of coping that mean that both the older person and the person with learning disabilities are looking after each other; without each other’s support, neither person would be able to remain living independently within their local community. This is known as ‘mutual caring’⁶⁵

The Foundation for People with Learning Disabilities lists some of the main issues for people with learning disabilities who are carers:

- Feeling proud of helping out and returning the care and support that has been provided to them by their parents for so many years
- Not being recognised for their role as a carer
- Not being offered many choices about how support is provided or continuing to care
- Fear of being separated if workers discover the extent of the mutual caring that is happening
- Lack of information that is accessible and easy to understand information about e.g. rights as a carer, available support or health conditions of their relative

We have found evidence of all these issues in our study. They are issues for many carers but are often more of a struggle if the carer has learning disabilities. We also found that the people with learning disabilities in our study had not been given sufficient recognition of their emotional capacities. In some cases, even their long term support workers present at the meetings were surprised by how well clients they had known for years could express and reflect on their situation. The distress around situations where a loved one has cancer and may be dying is inevitable, but it certainly seems that some of the suffering of people with learning disabilities could have been avoided if they had been given an opportunity to share their worries with a professional, someone they did not feel the need to protect.

The issue of mutual caring is further complicated by the fact that people with mild to moderate learning disabilities may not be known to services, and may not usually need very much additional support beyond their own families, friends and social networks. Without information about and access to a range of mainstream services, and help at points of crisis, the needs of people with learning disabilities may escalate to the point where their usual support networks break down⁵⁷.

5.4 The impact of bereavement on people with learning disabilities

All but one of the participants had been bereaved through cancer; for almost half of the participants, this included a parental bereavement. This clearly affected their responses to

our questions. Some found it difficult to think back to when the person was ill, as they were so overwhelmed by the fact that the person had died: 'I saw my mum die'; 'He died at five o'clock in the morning'. Faced with the question 'What do you think Jim is worried about?' the worry that Jim's father will die featured strongly. Much of the sessions were spent talking about the people who had cancer and who had died. Some participants showed substantial grief, even many years after the death.

The effects of grieving would probably be found in any focus group consisting of people who had lost a loved one. There are, however, complicated issues for people with learning disabilities who have been bereaved, and this is particularly true for parental bereavement. Blackman ²⁶ describes this vividly in her seminal work on loss and learning disability. People with learning disabilities are at increased risk of grief becoming complex, because of a range of factors:

- Their understanding of the concept of death, and being shielded from the reality of death throughout their lives
- 'Disenfranchised grief', where either the loss or the mourner is not acknowledged
- Complications in forming early attachments with a parent; problems with early attachment have been linked to complicated grief
- Difficulties with keeping the memories of the deceased alive
- Lack of recognition for their grief

The experience of being 'protected' from bad news, as well as from the outward expressions of grieving, only added to people's distress. Some of the participants in our study found themselves unable to talk about the person who died with those around them, particularly with their own families. For those who did not talk easily, the opportunities for sharing their grief were even more limited. Participant 14 found it very helpful to look at photographs of her uncle and of his funeral over and over again, but her mother, although very supportive, acknowledged that she herself found this too painful. She couldn't cope very well with the directness of her daughter's grief.

The finding that family members were unable to provide support to the person with learning disabilities during the period of bereavement as well as during the time of ill health (as we

have seen above) echoes the findings of Dowling et al ⁵⁸ in their study contrasting two different bereavement interventions: one where bereavement support was provided by an outside bereavement counsellor in dedicated sessions, and one where such support was offered within the participants' own social circle. Whilst family members and direct care givers considered the provision of emotional support as part of their role, they were in fact unable to provide such support for a variety of reasons, including a fear of the emotional repercussions and difficulties in coping with the issue of loss themselves. Outside counsellors, on the other hand, achieved marked improvements in participants' coping with the loss. Participants relished the experience of talking to someone about their feelings, which they were unused to.

5.5 Reflections on methodology

5.5.1 Gary's reflections in his own words

“We asked people about their experiences and their ideas and opinions. The groups were very different. Each person had their own voice. They all wanted to be heard. Some were very opinionated. Before we arrived on the scene I don't think they had had anyone to talk to about it. It was like a damn had burst and everything just flooded out. Or taking a cork out of a bottle and everything spews out like a fountain. They didn't have to stick to the question. They could talk about what they felt. A couple of people almost felt betrayed because they hadn't been told about their mum or dad having cancer. One person wasn't told about his other half until she practically passed away. Every time we met it was like he was ready to explode, he was that angry. It was like he had a ticking time bomb inside him. People really liked it when we did the made-up stories. I think they can relate to stories. They can associate it with their lives. They say things like 'I was like that' or 'my dad was like that'. The support staff often had an expression of shock, horror and amazement on their faces, as if they were saying, 'This person never said this before. I never heard them say that.'”

It was good to do the groups together. I think the group expected Niki and Irene to run it. Maybe they see Niki and Irene as the learned professionals. But they wouldn't have been so forthcoming if we hadn't been there. I don't use flowery words, I get straight to the point. I

just stirred the cauldron a bit and got the ball rolling. I've done teaching of medical students at the hospital. I was used to sharing my personal experiences in a group. That helped me. Afterwards we worked towards the end-game. When you've done several focus groups, they raise key points that are almost identical to each other. Once you start hearing the same thing over and over, you begin to think: aha... we're on to something! We talked about how to present our findings in a way that's easier for people to understand. You couldn't present the whole focus groups. It would be too much."

5.5.2 Amanda's reflections in her own words

"All the people in the groups were surprised how Gary and I were helping to run the group. They didn't expect that people with learning disabilities could do this job. They were thinking that maybe they could go and do a similar thing. Because Gary and I have learning disabilities, they listen to us. They were so surprised when I told my story! I know some people don't get well from cancer, and they were surprised that I did. What helped me is the course I had done when I worked at a theatre company. To be in front of a group, and to talk in a group: I was already used to that from what I'd done before. The theatre company has given me the confidence to talk in a group.

I liked working as a team. We did things together, instead of doing them separate on our own. For example, we did warm-up games at the beginning of each session, and we got everyone to join in. I really liked meeting different people in the groups. We learnt from them too. For example, what it is like for other people to have been through cancer, and hearing about their families. The people in the groups were really pleased that we came to visit them, because they could talk to us about anything they wanted to. When I talked to my support worker afterwards, she was amazed at how much people in the group shared."

5.5.3 The presence of support staff

Support staff, advocates or family members were present at all focus groups and two interviews. Their role has mostly been highlighted in the literature as a positive one, as they can interpret participants' communication³⁷, enable participants to understand what is required of them³⁵ and provide general support³⁸. We have certainly found it valuable to

have someone in the group who knows the participants and can provide support. This included accompanying participants to withdraw temporarily if they became distressed.

However, there is a price to pay for having supporters present. They may not simply facilitate discussion, but also have a clear opinion of the ‘right’ responses to the questions raised by the facilitator, and encourage participant to express ‘desirable’ responses⁵⁹.

Llewellyn⁶⁰ states that supporters should provide support, not opinion.

We found that whilst some supporters clearly helped the participants to express their ideas, others sometimes put forward their own, thus inhibiting contributions from the people they supported. Support workers chipping in with their opinion was rarely helpful. We learned the importance of briefing supporters clearly about their role before each session. At the first meeting of group C, I had failed to brief a support worker properly. This support worker began to contribute his own very raw experience of having a friend with cancer. He was clearly angry and upset. It left the group (including myself!) rather stunned and not sure how to respond. I took him aside after this and explained that his role in the group was not to give his own opinion, but simply to enable and facilitate the participant to give his. I gave him the option of finding another member of staff to support his client if the topic was too upsetting for him. He chose to remain, and kept quiet for subsequent meetings. When he was absent during the third meeting, it became clear how much his client was aware and protective of his needs:

‘My support worker, he’s got a problem. His mate is actually dying now. His mate is going to die soon, in the next six months. My support worker is finding it hard. He’s not coping with it. He needs support. It’s doing his head in.’

5.5.4 Co-facilitators with learning disabilities

The decision whether or not to include researchers with learning disabilities in the team is not simply a question of morals or rights (‘Nothing About Us Without Us’). If researchers with learning disabilities carry out data collection as co-facilitators or interviewers, this becomes a methodological issue. The research team needs to be aware of the advantages and disadvantages of having co-researchers with learning disabilities.

There has been very little literature about this issue, which meant that working with co-facilitators with learning disabilities in this study was a learning curve for all of us. When we started running the focus groups, it soon became clear that in order to facilitate effective sharing within the group, what was needed from the co-facilitators with learning disabilities was not the ‘impartiality’ we had tried to prepare ourselves for. On the contrary: their facilitative power lay in their ability to share of themselves within the group, to give their opinion about participants’ contributions and to resonate with them, thereby helping the participants to keep contributing. The researchers with learning disabilities acted as role models for the rest of the group. They helped the group to see that it was possible and acceptable for people with learning disabilities to speak up in the presence of ‘learned professionals’ like Irene and Niki. In openly challenging Irene sometimes within the focus group (‘I’ve never understood that word! What does it mean?’) and in their ability to share their own experiences and opinions, they acted as role models for the rest of the group. What was particularly impressive and helpful was their ability to comment with warmth and recognition on other people’s contributions. This validated participants’ experiences.

Participant 9: If his dad passed away, he would have to look after the family, wouldn’t he. He is the man of the house.

Gary: Yeah, I see what [*participant 9*] is saying. Because Jim is now almost like the man in the house, if you see where I’m going. So he’s probably thinking, right, where do I go from here.

Participant 9: Yeah.

Gary: I see what [*participant 9*] is saying.

Gary and Amanda kept the group dynamics and the discussions going and the participants contributing. This was the case even on the few occasions when they openly disagreed with a participant, as in this example, where Group B discussed who would be a good person to talk to about someone’s cancer:

Participant 10: It could be a family doctor. Or a priest.

Gary: No, if a priest would come to talk to me about cancer, that would frighten me out of my skin!

It became clear that this kind of facilitation could only come from researchers with learning disabilities. If Irene had said what Gary said, it is likely participant 10 (and other participants alongside her) would become much more wary about contributing their thoughts.

The focus group participants themselves agreed that it was good to have Gary and Amanda in the group. They reflected afterwards:

‘They [*Gary and Amanda*] helped a lot.’

‘I wouldn’t find it easy to explain things if they weren’t there.

‘It breaks the ice with the group when you [*Gary and Amanda*] speak.’

This is in line with Fern⁶¹ who found that the most effective facilitators come from the same population as the focus group participants, and with Llewellyn et al⁴¹ who found that participants are often willing to share feelings and insights in the presence of people they perceive as being like them in some way.

Co-researchers with learning disabilities will need considerable support, particularly if the topic of the research is sensitive. This needs to be taken into account when planning the research in terms of time and finances. From a methodological perspective, incorporating the contributions of co-facilitators with learning disabilities in the analysis is important but under-explored. Irene and Gary had made a serious and fairly successful attempt to do this once before¹⁸, but the focus group and interview data were somewhat different. We had to experiment and see what worked well. Doing qualitative analysis the way it is described in the textbooks is too complex for most researchers with learning disabilities. Analysing data requires a certain level of intellectual ability and capacity for abstract thinking that is, by definition, beyond most people with intellectual limitations; however, as we have demonstrated, their input into the process is extremely valuable. It would be hugely helpful if other inclusive research teams could publish their experiences with collaborative data analysis, so that the academic world can work towards accepted procedures for rigorous data analysis that includes people with learning disabilities.

5.6 Study limitations

5.6.1 Representativeness

It is worth noting that people with learning disabilities are a highly heterogeneous group with wide variations not only in their intellectual ability but also in their ability to think in abstract concepts and in their life experience. Our study sample could not be representative of the entire population of people with learning disabilities. The greatest limitation of this study was the fact that only people with mild and moderate learning disabilities who had some verbal skills could take part. We noted differences between groups in terms of intellectual and verbal ability, with participants in group A having more severe limitations. This affected the findings, as we have seen in the discussion of the ‘voting results’.

5.6.2 People with severe and profound learning disabilities

Accessing the viewpoints and experiences of people with severe and profound learning disabilities would require a different methodology such as ethnography (Agrosino, 2004), which is time consuming and expensive. The study sample was further limited by logistical constraints and issues of gate keeping (relying on a third party to provide access to participants), making it difficult for the research team to access a wide cohort of potential participants from which to sample purposively. This problem has been noted by others attempting to do research around cancer with people with learning disabilities (McCann et al., 2007).

5.6.3 Generalisability

Given the limited sample size, the findings need to be treated with caution and are not easily generalisable. The aim of studies of this kind is to generalise to theory, highlighting potential issues and perspectives that may not have come to light previously. In particular, the findings are certainly not generalisable to a population of people with severe and profound learning disabilities, although some of the support needs of people within that population could be proposed from our study findings. This includes, for example, the finding that people with learning disabilities benefit from being included and supported.

5.6.4 Retrospective design

A further limitation of the study is the fact that it was retrospective, relying on participants' memories of events that, for some, had happened a number of years earlier. The accuracy of their memories cannot be guaranteed. What we could establish is not so much *what happened*, but *how they experienced* what had happened. This made it more difficult to find out what people's support needs had been *during the illness* of their loved one. How participants remembered their needs at the time was inevitably coloured by their subsequent experiences, which for most participants included significant bereavement. In order to investigate more reliably what the support needs are of people with learning disabilities who have a relative or friend with cancer, a different (and more expensive) study design is needed, for example, a longitudinal design (such as repeated interview sessions during and after the patient's cancer experience) or a design that includes participant observation.

6 Conclusions and recommendations

This is one of the first studies looking directly at the needs of cancer patients' relatives, partners and friends with learning disabilities. Despite the study limitations, the findings of the study are striking and significant. There is a clear need for proactive support on a number of levels:

- emotional (eliciting worries and concerns, and providing emotional support)
- practical (ensuring people with learning disabilities receive support in helping their families)
- informational

In this section, we address the question whether the needs of people with learning disabilities who have a relative or friend with cancer are different from those of the general population. We also aim to answer our research questions (see Section 1.2): What are their cancer information and support needs? What barriers do they face to receiving adequate information and support? Finally, we give our recommendations for practice, the development of resources, and future research.

6.1 Are the needs of people with learning disabilities different from those of the general population?

Many people with learning disabilities may cope very well in manners similar to those of the rest of the population. However, such coping is often dependent on the support received, both from personal social networks and from professionals. The difference for people with learning disabilities, particularly those with mild learning disabilities, may be not so much coping difficulties that are inherent in their learning disabilities, but difficulties arising from a lack of outside recognition of normal needs.

There are further complications arising from complex family relationships, which may include 'protection' (with family carers protecting the person with learning disabilities from

knowledge and distress, and the person with learning disabilities protecting their families from their own feelings and worries). There may also be issues of ‘mutual dependency’ and mutual caring. People with learning disabilities are less likely to be recognised as a care giver of a cancer patient who, traditionally, has cared for them; they are therefore less likely to receive the support they need in this caring role.

Complications inherent in the presence of the learning disability itself arise from difficulties in processing new and complex information. Information around cancer, and all the changes that brings, is inevitably complex. The processing of such information (particularly abstract information), and the assimilation of life changes, takes more time and effort for people with learning disabilities.

6.2 What are the cancer information and support needs of people with learning disabilities who have a relative or friend with cancer?

Our study found that support needs were more important than information needs. Support needs include the need ‘to be included’ rather than protected from what is happening. More important than the actual need for more cancer information was the need for someone willing to listen to questions and concerns, and someone to offer a supportive presence. We can list the most important support and information needs as follows:

- To be included and not protected from the situation. This means being an active part of the family unit, and being part of what is happening.
- To have someone who can listen to questions and concerns, and who can offer a supportive presence. This could be anyone – for example, a family member, a friend, a support worker or other professional.
- To have access to information that is easy to understand.
- To have sensitive bereavement support.

We will expand on these needs in the recommendation section (6.4).

6.3 What are the barriers people with learning disabilities face to receiving adequate information and support when a relative or friend has cancer?

In this study, we identified the following barriers:

- People with learning disabilities tend to ‘keep quiet’, and often do not ask questions or express true feelings to those who might be able to help.
- People with learning disabilities lack insight into the roles of outside professionals, and how they might help.
- There is a lack of opportunities for people with learning disabilities to share their feelings and experiences with peers.
- Services do not always recognise ‘mutual caring’ roles.
- People with learning disabilities are not given enough recognition of their emotional capacities
- Much of the available professional support is based on verbal communications, which is less easily accessible to people with learning disabilities.
- People with learning disabilities lack access to easy-read information materials, even if they exist; they rely on others to enable them to access such materials.

It must be noted that the barriers we have identified are based on the perspectives of people with learning disabilities, which was within the remit of our study. Some further barriers have not emerged directly from this study, but can be speculated following reflection on our findings and on the available literature. These include:

- A lack of recognition by professionals that people with learning disabilities need their support.
- Uncertainty among health care professionals about how to communicate with people with learning disabilities.
- Insufficient support for families in helping relatives with learning disabilities cope with the situation.

6.4 Recommendations

6.4.1. General recommendations

RECOMMENDATION 1

If a cancer patient has a relative, partner or close friend with learning disabilities, whose life will be affected by the illness, these should be offered professional support as a matter of course. Staff should aim to increase their understanding of the individual with learning disabilities, and any special issues or coping strategies they may have. They should talk to the cancer patient and other relatives and to the community learning disability team about ways in which the person with learning disabilities can be supported.

This study has found that people with learning disabilities are unlikely to ask for support or make their needs known. Most will not know that professional support might be available to them. However, like all relatives and friends of cancer patients, they are likely to experience feelings of distress and worry. These can be exacerbated by a lack of involvement in the situation. People with learning disabilities need a supportive presence: someone who can listen and respond to any worries.

Cancer and palliative care nurses are in a unique position to provide such support. Simply giving some time and attention to relatives, partners and friends with learning disabilities will be hugely beneficial. Staff should be proactive in this.

However, it can sometimes be a challenge to identify relatives, partners or close friends with learning disabilities, as patients might not mention them; some might not visit the patient; and their learning disabilities might not be immediately obvious. One way staff could pick up information about vulnerable relatives is by asking the patient: *“Is there anyone at home, or close to you, who needs your help or support?”* The presence of such vulnerable people within the patient’s social circle should be highlighted in the patient’s notes.

If the person with learning disabilities is known to a community learning disability team, cancer and palliative care professionals should involve this team support and ask for their

input on effective communication and support strategies. If the person is not known to a community learning disability team, it is worth considering whether a referral should be made.

RECOMMENDATION 2

Staff should be aware that family or carers do not necessarily provide adequate support or information. They should offer support to families, paid care staff and learning disability professionals, so that these are better able to support the person. This includes passing on factual information about the cancer; advice on including the person in what is happening; and advice on normal emotional responses.

It may be that the best people to support the person with learning disabilities are those already close to them – such as families or learning disability staff. Many people with learning disabilities look to their families and carers for support and information. For some people with learning disabilities, families and care staff are crucial in understanding and helping with communication. However, families in particular may be protective of the person with learning disabilities and may not realise that this protectiveness can have a negative effect on the person's coping. The cancer patient him- or herself will be in a particularly difficult position of coping with their own illness as well as with concerns for their relative or friend with learning disabilities. In addition, this study has found that people with learning disabilities themselves are protective of their families and carers, and may not indicate their own needs and worries.

Health care professionals, including cancer and palliative care staff, should be aware of these complexities, and offer support to families and carers. This includes encouragement to talk about the situation and include the person; reassurance that it is normal for the person to show strong emotions; and factual information about the cancer and treatment, so that this can be passed on or reinforced to the person with learning disabilities in a way he or she can understand. This does not negate the need for health care professionals to offer support to the person themselves (as in Recommendation 1). However, support from health care professionals is only one part of the picture; people with learning disabilities rely on on-going support and reinforcement of key messages within their own social settings.

RECOMMENDATION 3

Professionals should check whether any relatives or friends with learning disabilities have themselves taken on caring responsibilities. If so, they should be involved as partners in the provision of treatment and care for the patient, and offered adequate support. Professionals should also check whether the patient has anybody within their social circle who is reliant on their care or support.

People with learning disabilities are less likely to be recognised as carers, and less likely to be listened to. However, many have taken on caring roles, sometimes in a relationship of ‘mutual dependency’ and ‘mutual caring’, where neither the patient nor the person with learning disabilities could manage to live independently. Health care professionals should ask the person with learning disabilities whether they do anything to help look after the patient. If so, it is even more important that they are fully involved and included in discussions and decisions about the patient’s treatment and care. They should be given recognition for their role and offered any support they might need. Staff should be aware of the fact that both the patient and the person with learning disabilities might be worried about relinquishing their responsibilities or being separated.

RECOMMENDATION 4

Professionals should be aware of the high likelihood that people with learning disabilities experience complicated grief, and ensure that adequate support is in place.

Many people with learning disabilities can cope with bereavement without any specialist support or counselling, but in order to cope well, it is important that their grief does not go unrecognised and is not disenfranchised. Cancer and palliative care professionals should be particularly alert to the hidden needs of people with learning disabilities who are ‘protected’ by their families from knowledge about death or dying. They can help families by explaining that the person with learning disabilities will have to find out about an impending death sooner or later, and that people who experience a death as ‘sudden’ (i.e. they had not been aware that the patient was going to die) have more difficulties in coming to terms with the loss.

As well as supporting families in being inclusive, referrals should be made to learning disability professionals if a death is expected. This is particularly important for impending parental bereavement, which can have a profound impact, not only emotionally but also socially – particularly if the person lives with their parent or is dependent on the parent in some way. Multiple concurrent losses (for example, where the death of a parent means an immediate move out of the family home) should be avoided as much as possible.

Cancer and palliative care services may have their own bereavement support strategies or a bereavement support service. People with learning disabilities should not be excluded from such support. There is evidence that outside bereavement support (as opposed to bereavement support provided by the person's own family or paid care staff) is effective for people with learning disabilities⁵⁸, but mainstream bereavement counsellors may need some extra training in order to adapt their services to the person's needs.

RECOMMENDATION 5

Training on 'learning disability' should be made available for health care staff. Such training should include: the impact of learning disability on people's lives; communication with people with learning disabilities; and the use of accessible information materials.

Staff without training tend to stereotype people with learning disabilities and they are less likely to listen to them⁵⁵. Staff training should be aimed at changing attitudes and improving a knowledge base. Staff training should include:

- What is 'learning disability', and how does it impact on people's lives?

It can be particularly effective to involve people with learning disabilities as co-trainers as a way to dispel myths and fears about learning disability. There are positive examples throughout the UK of such involvement.

At Severn Hospice in Shropshire, a staff nurse made links with the local community learning disability team and a service user advocacy group to provide training for hospice staff.

- How to communicate effectively with people with learning disabilities

If the person with learning disabilities is visiting the patient, health care professionals should communicate directly with this visitor. They could offer to explain the situation or answer any questions. Simply demonstrating availability, for example, by sitting down next to the person for a few minutes, can be hugely helpful and may build up trust, even if the person doesn't seem to communicate in a way that is easy to understand.

In most situations, using simple, clear sentences without jargon, and being kind and open, is enough. Many people with learning disabilities, particularly mild learning disabilities, may have sufficient verbal capacity to be able to communicate in a way the nurse can understand. Using simple, straightforward and non-euphemistic language needs vigilance⁵⁰. We may not even be aware how our every-day expressions can cause confusion. Staff should not only think about which words they will 'say', but how these will be 'heard'. Saying, 'I'm sorry that you have lost Grandpa', may leave the person wondering why we don't start searching for Grandpa. An 'organ' is something you play in church; a 'positive result' is very good news indeed, so 'I'm afraid your mum's test was positive' may make absolutely no sense.

Health care staff should know where to find help with any additional communication issues and needs⁵⁰. When communication needs are more complex, such help could come from a learning disability professional. All nurses and other health care staff should know where to find such professionals and collaborate with them.

- How to use accessible cancer information materials effectively

To support the provision of adequate support, nurses will need to familiarise themselves with the accessible cancer information materials available (see Section 8). However, information materials are only as good as the person using them, and do not negate the need for further communication and support. Every person with learning disabilities is different, and the ways in which they use pictures can be varied. Using accessible materials should support communication, rather than be the prime source of communication. Effective use of accessible resources is likely to elicit questions and concerns that will need to be addressed. The local community learning disability team may be able to offer advice on using accessible resources.

RECOMMENDATION 6

Further accessible materials should be developed to help people with learning disabilities make sense of a range of difficult situations and experiences.

There is now a range of general cancer information materials available that are accessible (see Section 8). However, there are gaps in provision that should be addressed. There are resources aimed at relatives and friends coping with bereavement, but a lack of resources aimed at supporting relatives during the patient's illness. We suggest that new resources should be developed that have a focus on the patient's relative or friend, looking at changes and emotions from their perspective. For example:

- visiting the patient in hospital
- looking after the patient at home
- feeling lonely and worried
- talking to someone about feelings and worries
- seeing someone close to you in the last stages of life

RECOMMENDATION 7

In order to understand more fully the support needs of family and friends with learning disabilities, further research is needed in a number of areas, including: demographics; the needs of people with severe and profound learning disabilities; the perspectives of other stakeholders; and the effectiveness of accessible cancer information materials. Such research should include people with learning disabilities, both as participants and as members of the research team.

- There is a lack of demographic data about cancer and learning disabilities. This includes not only how many of this population have cancer themselves, but also how many are carers of a cancer patient. Demographic research will give a clearer indication of the resources needed to support these groups in the future.
- Our study has only accessed the views and experiences of people with mild and moderate learning disabilities who had sufficient verbal ability. Research is needed into the needs of a wider group of patients' relatives and friends with learning disabilities, including those with severe and profound learning disabilities. How can their needs be assessed or interpreted, and how can they be met?

- Our research findings are influenced by the fact that the study was retrospective, with many participants having suffered cancer-related bereavements. Non-retrospective research would be useful, involving participants for whom the experience of being a relative/friend of someone with cancer is current. This would highlight how people's support needs change over time. Such studies, however, require high levels of researcher time and are therefore expensive.
- The perspectives of other stakeholders would be valuable, including family and other carers, paid care staff, learning disability professionals and cancer/palliative care professionals. A triangulation of data from different stakeholders, including people with learning disabilities themselves, would be particularly helpful.
- Cancer patients and their families who have a relative or close friend with learning disabilities are likely to worry about them, adding to the patient's levels of distress. Research is needed into the way in which cancer patients and their families can be supported when one of their family members has learning disabilities. What are their worries and concerns? How can they be helped to include and support the person with learning disabilities?
- The development of accessible resources is expensive, and it is therefore important to assess how effective these are. For example, what kind of materials work well in what kind of situations, and for which client groups? What are the skills needed from carers or supporters in helping people with learning disabilities make the most of these materials? What is the extent and impact of people's visual literacy (the ability to interpret and make meaning from information presented in images)?
- Finally, this study has strongly demonstrated the benefits of including people with learning disabilities in researching areas that affect their lives, both as participants and as co-researchers. The additional financial resources needed to enable people with learning disabilities to take part in research are well worth it, as their involvement will add to the reliability and validity of the findings.

6.4.2 Recommendations for specific stakeholders

Many of the above recommendations will need to be acted on by healthcare professionals who have direct contact with the patient and their relatives and friends. However, in order to do so effectively and to ensure systemic change (rather than rely on the enthusiasm and

commitment of individual staff), there needs to be support on organisational, policy and management levels.

Service providers

In order to give relatives and friends with learning disabilities the same access to support as others, and in order to meet their specific needs, we recommend that cancer and palliative care service providers put in place certain measures.

- Service providers should set up and support links with local learning disability teams and make information about these teams available to their staff. *Recommendations 1, 2, 4 and 5*
- Patients should be asked whether there is anybody with vulnerabilities within their social circle who might need support. Relatives and friends should be asked whether they have any caring responsibilities for the patient. This information should be recorded and should trigger a pathway of supportive measures. *Recommendation 3*
- Accessible information materials should be made available to staff, for example, on the wards or via the organisation's intranet. *Recommendation 5*
- Service providers should offer opportunities for people with learning disabilities to get acquainted with their service, for example, by holding 'open days' or tours. This will help break down barriers for both staff and people with learning disabilities.

Trainers

- Those with responsibility for the provision and regulation of clinical training, must ensure that curricula include mandatory training in learning disabilities. It should involve people with learning disabilities in providing training. *Recommendation 5*

Bereavement services

People with learning disabilities are unlikely to indicate their bereavement support needs, and therefore services will have to be proactive.

- Bereavement service providers, both within cancer and palliative care services and independent bereavement services, should train their staff to include people with learning disabilities within their service provision. *Recommendation 4*
- If a person with learning disabilities has been (or will be) bereaved, an assumption should be made that they will need support. Services should implement a pathway where

they check whether the person is supported within their social environment and whether they need additional support. ***Recommendation 4***

Funders

Improving the support for relatives and friends who have learning disabilities does not only have a positive effect on them, but is likely to have benefits for the whole social circle, including the patient. Much can be achieved through a focus on practice developments that do not require many additional resources (for example, making links with local learning disability teams). However, in order to achieve all the recommendations, funding is required.

- Funding bodies with a remit to support training should put some resources into ensuring that training about learning disability is available to all staff. ***Recommendation 5***
- Developing good accessible resources is expensive and therefore reliant on external funding. It is a long process involving people with learning disabilities, a range of professional experts, and artists. ***Recommendation 6***
- Research cannot be done without funding. Funders should prioritise research that is likely to provide insights into how service provision can be improved. Research involving people with learning disabilities is more expensive, but if done well, it is likely to yield valuable results. ***Recommendation 7***

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8 Resources

Some of the resources below are developed to support people with learning disabilities who themselves have cancer and/or need palliative care. However, they can also be used to support people who have a relative or friend with cancer, or someone close to them who is at the end of life.

Most of the information in this section is taken from the website of the Palliative Care for People with Learning Disabilities Network (PCPLD Network): <http://www.pcpld.org/> The PCPLD Network aims to enhance collaboration between service providers and carers, and promote best practice. It is currently chaired by Irene Tuffrey-Wijne, who also wrote the website, including the Resources section.

Accessible resources for people with learning disabilities

CHANGE cancer books

<http://www.changepeople.co.uk/productDetails.php?id=2551>

Three easy-read information books about cancer for people with learning disabilities, plus three accompanying books for their carers, The titles are:

Symptoms, screening and staying healthy

Diagnosis and treatment

Palliative care, end of life care and bereavement.

The books have been made available free of charge by Macmillan Cancer Support:

<http://be.macmillan.org.uk/be/s-428-accessible-information.aspx>

EasyHealth

<http://www.easyhealth.org.uk/>

A website with links to health information that is easy to understand. Over 40 organisations from across the UK have put their information onto this website.

Books Beyond Words

<http://www.rcpsych.ac.uk/publications/booksbeyondwords.aspx>

Books Beyond Words is a series of picture books that has been developed to make communicating easier for these people with learning disabilities, and to enable discussion about difficult topics. The pictures are designed to help the reader make sense of what is happening to them, and help them to ask questions or share their concerns. Supporting text and guidelines are also provided for carers, supporters and professionals

Selected useful titles in the Books Beyond Words Series:

Getting on with cancer

<http://www.rcpsych.ac.uk/publications/booksbeyondwords/bbw/1901242846.aspx>

This book is based on the real-life story of the author, Veronica Donaghey, a woman with Down Syndrome. Veronica had cancer. The book tells the story of a woman who is diagnosed with cancer, and then has surgery, radiotherapy and chemotherapy. It ends on a positive note.

Looking after my breasts

<http://www.rcpsych.ac.uk/publications/booksbeyondwords/bbw/1901242536.aspx>
Designed to support women who are invited for breast screening, including a woman having a mammogram and a woman who demonstrates how to be aware of changes in your own breast.

Keeping healthy ‘down below’

<http://www.rcpsych.ac.uk/publications/booksbeyondwords/bbw/1901242544.aspx>
Designed to support women who are invited for a smear test.

When Dad died

<http://www.rcpsych.ac.uk/publications/booksbeyondwords/bbw/1904671047.aspx>

When Mum died

<http://www.rcpsych.ac.uk/publications/booksbeyondwords/bbw/1904671039.aspx>

These books tell the story of the death of a parent in a simple but moving way. (‘Jim’s story’ was taken from these titles – see Appendix 8.7)

When somebody dies

<http://www.rcpsych.ac.uk/publications/booksbeyondwords/bbw/1901242900.aspx>

This book shows people with learning disabilities that they need not be alone when they feel sad about someone’s death, and that talking about it to a friend or to a counsellor can help them get through this difficult time.

Am I going to die?

<http://www.rcpsych.ac.uk/publications/booksbeyondwords/bbw/9781901671626.aspx>

This book is based on the real-life experiences of people with learning disabilities who were terminally ill. It tells the story of a man who has learning disabilities and who is dying. The pictures follow him in his illness and his final days.

Going to the doctor

<http://www.rcpsych.ac.uk/publications/booksbeyondwords/bbw/1874439133.aspx>

This book illustrates a variety of experiences which may occur at a GP practice, including having one’s ears syringed, a physical examination, a blood test and a blood pressure check.

Going to out-patients

<http://www.rcpsych.ac.uk/publications/booksbeyondwords/bbw/1901242188.aspx>

This book explains what happens in out-patient departments, covering tests such as ultrasound, X-ray and hearing test.

Leaflets from the NHS screening programmes

The following picture leaflets are designed to give people with learning disabilities information about certain types of screening, and where to get further information. They can be downloaded in PDF format from the following links:

50 or over? Breast screening is for you

<http://www.cancerscreening.nhs.uk/breastscreen/publications/wwld-over50.html>

Having a smear test

<http://www.cancerscreening.nhs.uk/cervical/publications/wwld-smear.html>

An easy guide to bowel cancer screening

<http://www.cancerscreening.nhs.uk/bowel/publications/nhsbcsp-learning-disabilities-leaflet.html>

An easy guide to having a colonoscopy

<http://www.cancerscreening.nhs.uk/bowel/publications/nhsbcsp-colonoscopy-learning-disabilities-leaflet.html>

FAIR Multimedia booklets and CD Rom

<http://www.fairadvice.org.uk/fmindex.htm>

Fair (Family Advice and Information Resource) are an organisation who provide information for people with learning difficulties. Their booklets, CD roms and other materials have easy to read information on a range of subjects including checking for cancers, living with cancer, bowel cancer and maintaining good health.

‘We are living well but dying matters’. A DVD to encourage people with learning disabilities to express their thoughts and questions about death, dying and planning for the end of life. Available to download: <http://www.changepeople.co.uk/showContent.php?id=103>

Books and other publications for carers and professionals

Living with learning disabilities, dying with cancer: thirteen personal stories

by Irene Tuffrey-Wijne, published by Jessica Kingsley Publishers (2010)

<http://www.jkp.com/catalogue/book/9781849050272>

A powerful and moving account of the experiences of thirteen people with learning disabilities who were living with cancer, most of whom died of the disease. An invaluable resource for anyone involved in the care of people with learning disabilities who are facing cancer or other life-threatening illness, including staff working in learning disability services, health professionals and family carers.

Caring for people with learning disabilities who are dying

<http://www.worthpublishing.com/careld.htm>

by Noëlle Blackman and Stuart Todd, published by Worth Publishing (2005)

A concise, clearly written and practical book full of advice for service managers and staff working in learning disability services. It includes some advice on supporting friends and residents with learning disabilities.

Loss and learning disability

<http://www.worthpublishing.com/Online%20Store/indexshop.htm>

by Noëlle Blackman, published by Worth Publishing (2003)

This book is for care staff, therapists and counsellors working with people with learning disabilities. It talks about how people with learning disabilities can be affected by bereavement. It includes ways to prevent normal grief from becoming a bigger problems and ways of helping people when the grief process ‘goes wrong’.

The route to success in end of life care – achieving quality for people with learning disabilities

<http://www.endoflifecareforadults.nhs.uk/publications/route-to-success-people-with-learning-disabilities>

This publication from the National End of Life Care Programme aims to provide a practical guide which supports anyone caring for people with learning disabilities to ensure that those who may be in the last months of their life receive high quality end of life care. It may also be useful to health or social care professionals who come into contact with people with learning disabilities in clarifying what measures need to be taken to ensure that they can access appropriate care.

Training and advice

ENFOLD

ENFOLD c.l.c. provides bespoke courses and interventions to support the end of life care for people with learning disabilities. From diagnosis through treatment or into bereavement the training is based on both the most up to date research and significant hands-on experience of caring directly for people with learning disabilities who are ill or bereaved, their families and the professionals who care for them. A range of stand-alone courses are also on offer, including communication, end of life care and bereavement. The services is co-ordinated by Linda McEnhill. **Contact details:** Tel 01223 573173, Email info@enfold.org.uk

Useful services and organisations

Mencap

<http://www.mencap.org.uk/>

Mencap supports people with learning disabilities in a range of different ways. It works in partnership with people with a learning disability, and all their services support people to live life as they choose. Mencap's work includes:

- providing high-quality, flexible services that allow people to live as independently as possible in a place they choose
- providing advice through our helplines and websites
- campaigning for the changes that people with a learning disability want.

Mencap is an individual membership organisation and their work is shaped by what their members tell us about their needs and wishes.

Mencap has strong relations with a local network of more than 500 affiliated groups. Their local groups are individual charities in their own right, but Mencap works closely with them to ensure people with a learning disability and their families have support locally as well as nationally.

Community Teams for people with Learning Disabilities

These are specialist multidisciplinary health teams that support adults with learning disabilities and their families and carers by assessment, by supporting access to mainstream healthcare, and by providing a range of clinical interventions. Your GP or social services department should have the details of your local team.

Hospice Information Service, Help the Hospices

<http://www.helpthehospices.org.uk/hospiceinformation/>

Provides information about hospice care and about locally available hospice and palliative care services.

Macmillan Information Line

<http://m.macmillan.org.uk/cancer-information>

Provides practical, emotional, medical and financial advice for people affected by cancer in general. Also provides information about Macmillan services as well as other cancer organisations and support agencies.

Cruse Bereavement Care

<http://www.cruse.org.uk/>

Offers free bereavement counselling, support and information to anyone affected by death (including paid carers). Cruse bereavement counsellors have often been able to provide support to people with learning disabilities.

Respond

<http://www.respond.org.uk/>

This organisation supports people with learning disabilities, their carers and professionals around any issue of trauma, including bereavement.

Palliative Care for People with Learning Disabilities Network (PCPLD Network)

<http://www.pcpld.org/>

The PCPLD Network aims to enhance collaboration between service providers and carers, and promote best practice. There are opportunities for local networking and support.

9 Appendices

- 9.1** Research Advisory Group membership
- 9.2** Participant characteristics
- 9.3** Participant information sheet
- 9.4** Participant information DVD
- 9.5** Participant consent form
- 9.6** Interview guide for one to one interviews
- 9.7** ‘Jim’s story’
- 9.8** Nominal Group Technique: Ideas for voting
- 9.9** Role play: an example
- 9.10** Easy-read summary: Feedback letter to participants

9.1 Research Advisory Group Membership



Sheila Hollins (CHAIR)

Professor of Psychiatry of Learning Disability, St George's University of London

Paul Adeline

Self Advocate/Training and Research Advisor, St George's University of London

June Allen

Lead Cancer Nurse, St George's Healthcare NHS Trust, London

Jane Bernal

Consultant in Developmental Neuropsychiatry, Cornwall Partnership Foundation Trust

Jim Blair

Consult Nurse Learning Disabilities, St George's Healthcare NHS Trust, London
Senior Lecturer Learning Disabilities, Kingston University/St George's University of London

Peter Cranham

Self-Advocate, London

Leopold Curfs

Professor in Learning Disabilities; Director, Gouverneur Kremers Centre, Maastricht University, Netherlands

Valerie Emmons

Secretary, 'Improving the Cancer Experience' (Cancer Patients), St George's Healthcare NHS Trust, London

Sue Martin

Speech and Language Therapy Deputy Clinical Manager, Islington Learning Disability Partnership

Sue Read

Reader in Learning Disability Nursing, Keele University, Stoke-on-Trent

Susannah Seyman / Stuart Mills

Down Syndrome Association, London

Pauline Stanley

Family Carer, 'Caring Solutions', St George's Healthcare NHS Trust

Monica Stannard

Family Carer, 'Caring Solutions', St George's Healthcare NHS Trust

Patrick Stone

Consultant in Palliative Medicine, St George's Healthcare NHS Trust

Lucy Virgo

Families and Communities Project Worker, Mencap, Sheffield

9.2 Participant characteristics

Participant number	Sex	Age	Focus Group/ Interview	Who had cancer
1	F	42	Interview	Father, mother, aunt, uncle
2	F	58	Interview	Husband*
3	F	28	FG (A)	Grandfather
4	F	25	FG (A)	Grandfather
5	F	28	FG (A)	Mother, father, aunt
6	F	19	FG (A)	Aunt*, friend
7	F	29	FG (A)	Friend
8	F	51	FG (B)	Mother
9	M	60	FG (B)	Mother, father, partner, sister*, niece*
10	M	51	FG (B)	Sister
11	F	31	FG (B)	Father, mother*, grandmother
12	F	51	FG (B)	Mother, sister
13	F	62	FG (B)	Husband**, two friends
14	F	35	Interview	Uncle
15	F	48	Interview	Partner, friend, grandmother
16	F	34	FG (C)	Friend, brother
17	M	48	FG (C)	Mother
18	F	44	FG (C)	Mother
19	F	52	FG (C)	Partner
20	F	37	FG (C)	Mother, partner
21	M	63	FG (C)	Friend

* survived cancer; expected to live

**living but prognosis short

9.3 Participant information sheet



Information about the study

Version 1, 22/04/09

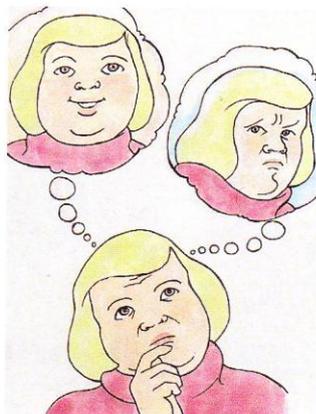


Hello, our names are Irene, Gary, Amanda and Niki.



We are doing a study.

A study is a way of finding things out.



Do you want to be in the study?

This information sheet tells you about the study.

It helps you to decide if you want to be in the study or not.



What is the study about?

Living with someone with cancer

What is it like for people with learning disabilities if someone they live with has cancer?

This is what we want to find out:

- The story of you and your family or friend with cancer
- What was it like for you? What was good? What was difficult? How did you feel?
- What did people do to help you cope?
- What could have been done better?
- What would you say to doctors, nurses and support staff? How should they do?



Why do we want to find out?

Lots of people get cancer. Many cancer patients live at home with their family or friends. We know it is often difficult for family and friends. They need a lot of help. We don't know what it is like for family or friends with learning disabilities. What help do they need? We need to find out.





What happens in the study?

There will be a group of people with learning disabilities.

We will meet with the group.

We will ask questions. We will listen to your stories.

It doesn't matter if you don't know any answers.

You can still listen to what other people say.



These things will help us think about the questions:

- We will look at some pictures about cancer and about how people feel.
- We will ask the people in the group to tell us their stories of what happened to them.
- We will think about ways in which people can help, and vote for the best ideas.



How often will we meet?



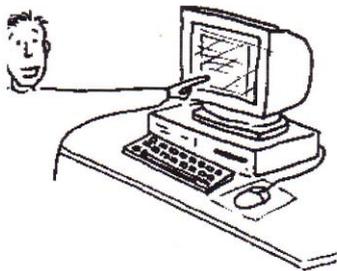
We will meet the group 4 times.

1. Meet you all and explain things.
Look at pictures.
2. Look at pictures again.
Listen to your stories.
3. Think about how people can help.
4. Vote for the best ideas.
Say goodbye.

How will Irene, Gary, Amanda and Niki remember what we said in the group?

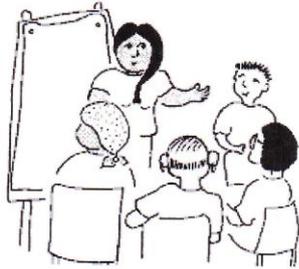


We will put a tape recorder on.



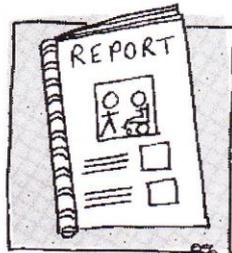
Afterwards, all your words on the tape will be written on a computer.

We will then destroy the tape.



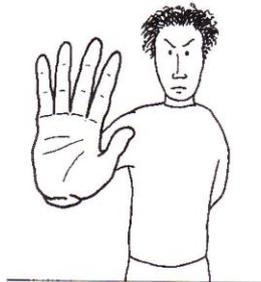
When we have finished, we will tell others what we have found out.

We will tell them: "This is a good way to help people with learning disabilities who have family or a friend with cancer."

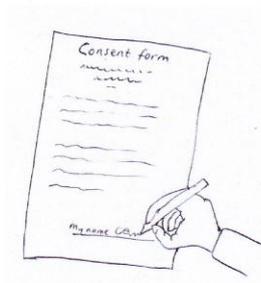


We will write in magazines about what we have found out.

Do I have to be in the group?

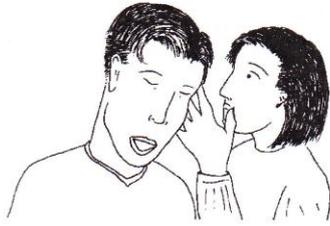


No. If you don't want to do it, that's OK. If you start in the group but you don't like it, you can stop. Nobody will be cross with you if you say no.



If you want to be in the study, you must sign your name on a special form, called a **consent form**.

If you find it difficult to write, someone else can help you.



Everything you say in the group is private. Irene will not tell anyone who was in the group.

Irene they will not write down your names. She will use pretend names instead.

Can the study upset you?



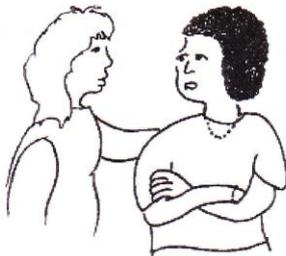
Some people may be upset by the study. It can be upsetting to think about your family or friend with cancer.

Maybe that person has died.

Talking in the group can make you feel sad sometimes.

Listening to other people's stories can also be sad.

You may get fed up with being in the group.



You must have someone (your group leader, a carer, family member or friend) who you can talk to about this.

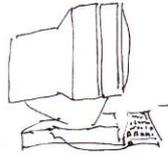
Remember you can always stop being in the group meetings.



You or your carer can phone Irene if you want to know more about the study.

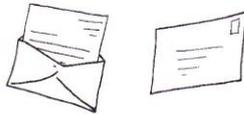


Irene's phone number is: **020 8725 5497.**



Or you can send Irene an email.
Her email address is:

ituffrey@sgul.ac.uk



Or you can write to Irene.
Her address is:

**St George's University of London
Division of PHSE
Cranmer Terrace
London SW17 0RE**

9.4 Participant information DVD

Script and DVD stills



Irene: Hello everybody!

Gary: Hello!

Amanda: Hi!

Niki: Hello!

Irene: My name is Irene.

Gary: My name is Gary.

Amanda: I'm Amanda.

Niki: And I'm Niki.

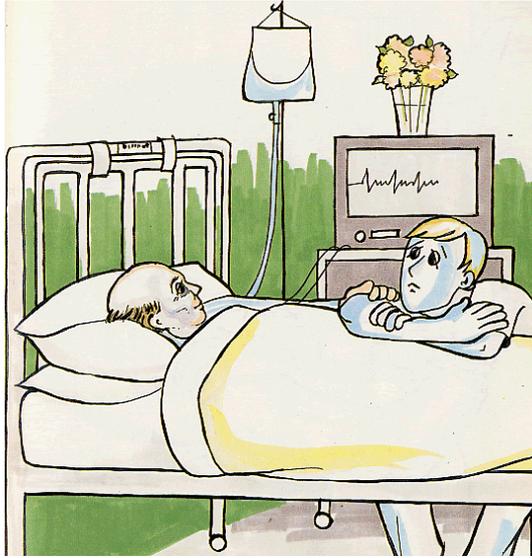
Gary: We are doing a study.

Amanda: What is a study?

Gary: A study is a way of finding things out that we want to know.

Amanda: What kind of things?

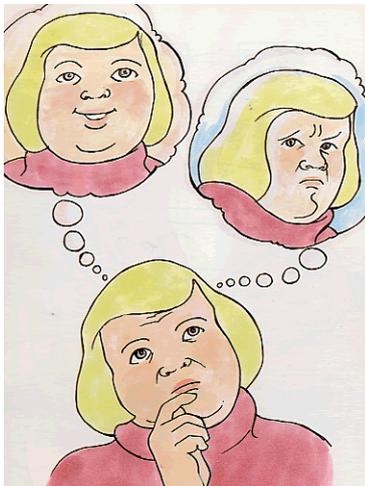
Gary: It's about cancer. We want to know what it is like if someone in your family or maybe a close friend has cancer.



PICTURE: 'Jim' sitting at his father's hospital bed, looking sad.

Amanda (voice-over): Do you know someone who has had cancer? What was it like for YOU?

Amanda: Do you want to be in the study? Let us tell you a bit more about it, so you can think about it.



PICTURE: Someone thinking



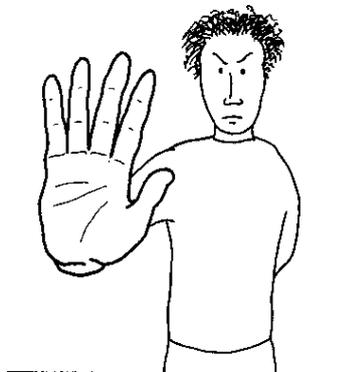
PICTURE: People sitting in a group around a table

Amanda (voice-over): Do you want to be in the study?



PICTURE: Smiley face; thumbs up [= Makaton sign for 'yes']

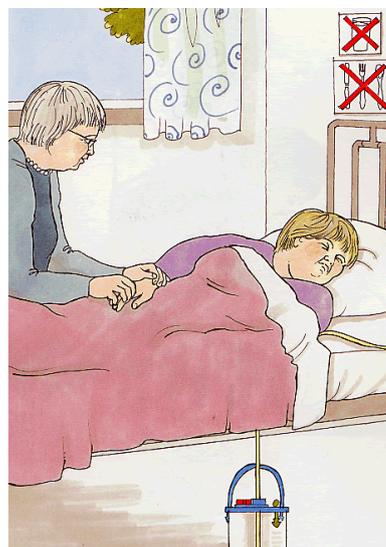
Amanda (voice-over): You can say yes.



PICTURE: Sad face; palm of hand facing outward [= Makaton sign for 'no']

Amanda (voice-over): Or you can say no.

Irene: As Gary said, this study is about cancer. Have a look at this picture [holding up a picture of a woman having chemotherapy]. This is a picture of Veronica. Veronica has cancer.



PICTURE: Veronica having chemotherapy.

PICTURE: Veronica lying in a hospital bed, with her mother at her side.



Amanda: I wonder what it is like for Veronica's family and friends.'

Gary: So do I. It must be hard'

Irene: Good point. What **is** it like if someone in your family, or your friend, has cancer?

In the group, we want to talk about cancer. I think everyone knows somebody who's had cancer. Now, or maybe before. I know I do.'

Gary: I do.

Amanda: I do.

Niki: Me as well.

PICTURE: People sitting in a group around a table

Gary (voice-over): Do you want to be in the group and talk about it with us?

Amanda (voice-over): Do you want to be in the group?

Amanda: When we get the group together, you will have to come four times. You can bring a support worker with you.

Gary: Anything you say in the group will be kept private.

Amanda: When we get the group together, you will have to come four times. You can bring your support worker with you. You will get paid 80 pounds.

PICTURE: Money (£80)

Irene: I am in charge of the study. I will be leading the group.

Gary: I am going to be helping to run the group. And to help you think about what you want to say, and to tell your stories.

Amanda: So am I. We want to make it fun for everyone. We are going to do some acting and show some pictures. And we hope that everybody will join in and have a good time.

Niki: I am the assistant of Gary, Amanda and Irene. I will take notes and put everything on this tape recorder, so we can hear again what you have told us.



Gary: You don't have to come to the group, but it would be nice to see you. And we'll have a good time.

Everyone: Bye!



9.5 Participant consent form



Consent form

Version 1, 22/04/09



I have seen the information about the **Living with someone with cancer** study.

I understand it.

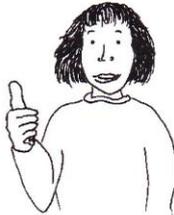


I want to be in the group.

I know that I can stop being in the group if I don't like it anymore.



I agree that everything we say in the group will be put on a tape recorder.



YES I want to do it



NO I don't want to do it

My signature _____

My name _____

Date _____

9.6 Interview guide for one to one interviews

The following is a guide only. Flexibility must be used when interviewing people with learning disabilities. Both the style and content of the questions must be adapted flexibly to suit individual needs and communication styles. If a supporter is present, he/she may be asked for help in enabling the interviewee to communicate their thoughts and ideas.

Explain the study

- The person will already have received the study information. Go through the information sheet again. Invite questions.
- Assess capacity to consent (if the person seems unable to give informed consent: terminate the interview).
- Sign consent form (if not already done so).

Tell me about the person who had cancer

The interviewee is invited to share their experiences, including:

- What was wrong with him/her?
- How did you find out?
- What happened (eg experiences of hospitalisation, symptoms, death of the person)?

How did you feel?

- What was it like for you when X had cancer?
What was difficult?
Was there anything good about it?
- How did it make you feel?
- How do you feel about it now?

What helped?

- What helped you to cope?
- What did (or didn't) other people do to help you?
- What advice can you give to doctors, nurses and carers, about how to support someone with learning disabilities whose family/friend has cancer?

OPTIONAL: If the person has difficulty answering the above questions:

The researcher will bring pictures, explaining the story of a young man whose father has cancer. She will ask the interviewee's opinion on who the young man might be feeling, what might be difficult for him, and what might help him.

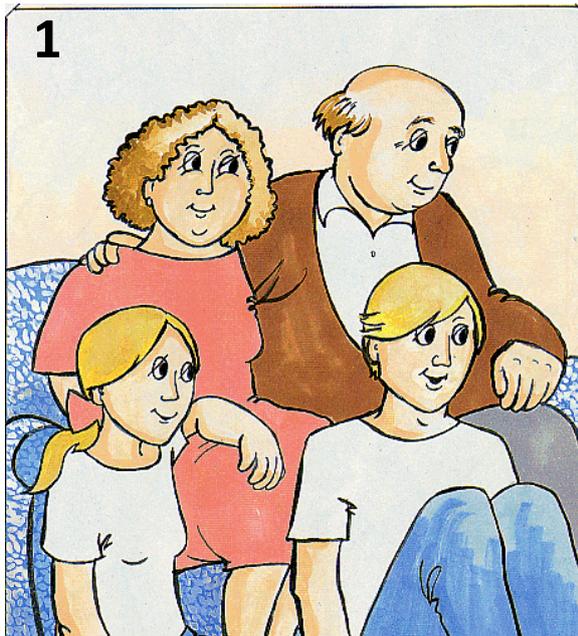
Ending the interview

- Thank the interviewee
- Explain what will happen with the data
- Assess the need for follow-up support
- Give the interviewee a phone number for Dr Irene Tuffrey-Wijne

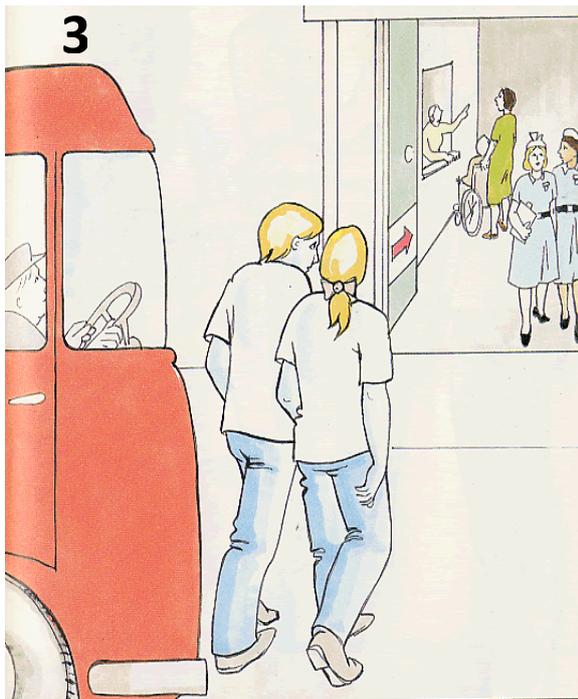
9.7 'Jim's Story'

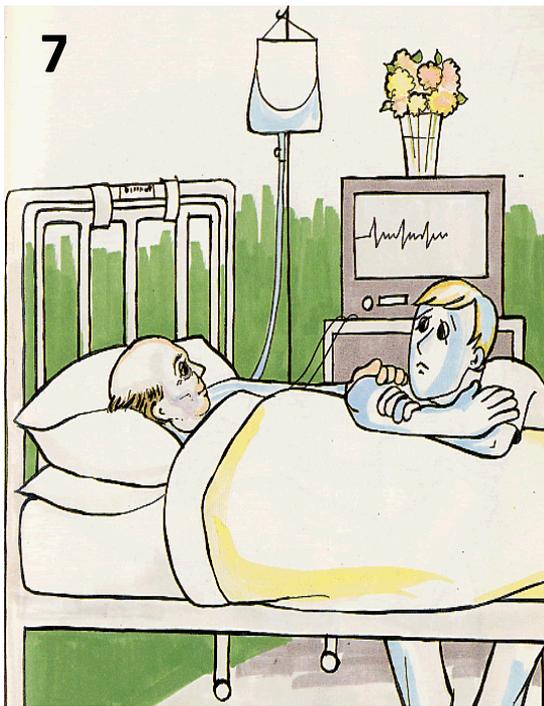
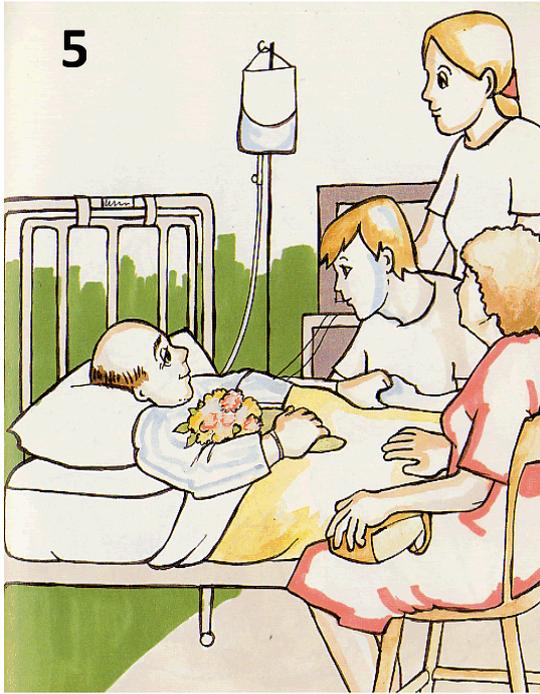
These pictures and questions were used to elicit participants' own ideas and experiences. 'Jim' is the young man in the pictures. Participants were asked what they thought was happening in the pictures, what Jim's experiences and worries might be, and what might help him.

The pictures are taken from 'When Dad Died' (see Resources, Section 8)



1
Jim's dad is ill



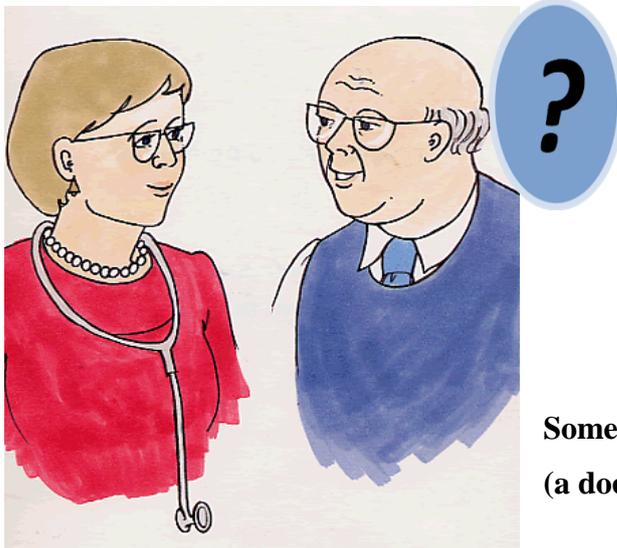


What is difficult for Jim?

What would help Jim?

9.8 Nominal Group Technique: Ideas for voting

The following nine pictures-and-word-cards were presented to the participants, who then 'voted' on these by selecting their five favourites, and ranking them in order of preference.



**Someone I can ask questions about cancer
(a doctor or nurse)**



**Someone to talk to about my feelings and
worries**



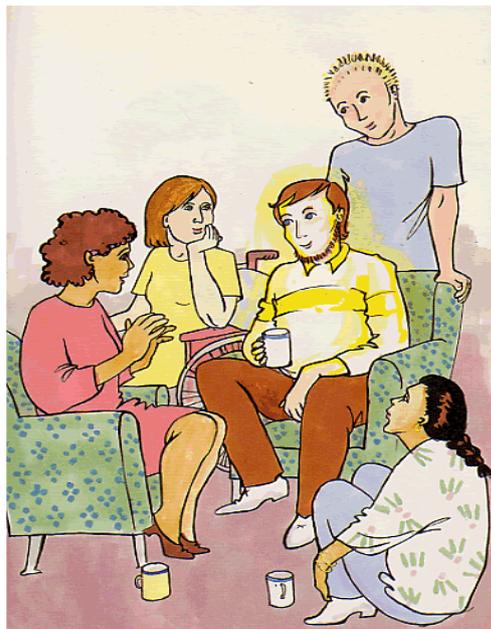
Easy words and pictures to explain cancer



Someone to help look after the ill person



**Photos of the ill person
to help me think and talk about them**



**Other people with learning disabilities
to talk together about our experiences**



Someone to support the rest of my family



My family, carers and doctor etc should tell me everything – I want to know



Someone to be with me

9.9 Role play: an example

We have shown the group slides of the fictional story of 'Jim' whose father is dying of cancer. We ask the question: 'What would help Jim?' The mothers of participants 1 and 2 both died of cancer.

Participant 20: *(immediately)* Talking to somebody.

Irene: Talking to somebody? Who would Jim like to talk to?

Participant 20: Go and talk to the doctor.

Irene: What would he say?

Participant 20: Just talk about the situation.

Irene probes but participant 20 isn't any more specific. Irene asks Amanda to act as the doctor, and asks participant 1 whether he would like to pretend to be Jim and talk to the doctor about whatever he wants. Participant 20 doesn't want to do it. Irene asks for another volunteer; participant 18 volunteers immediately.

Participant 18: Hello my name is Jim and my dad is ill. I need help.

Amanda ('Doctor'): What kind of help?

Participant 18: The kind of help that if he dies, how to cope. *[Pause]*

Irene directs Amanda, who is unsure how to respond, that she does not need to give any answers: she just needs to sit there pretending to be the doctor.

Irene: That was a good question, well done Participant 18, thank you. Participant 20, is that the kind of question? *(Participant 20 shakes his head)* What would YOU ask?

Participant 20 is now happy to take a turn. He swaps chairs with Participant 18. Irene tells him he can now pretend to be Jim and ask the doctor a question. He looks at Amanda:

Participant 20: What brings the illness on? They are no longer with you. *[Pause]*

Irene: That's a good question too.

Participant 20: One day they are alright and then suddenly they're not. How does that happen?

There is some discussion about this with the group. Participant 16 then asks: 'Can I have a go?' Participant 16 has autism and so far has contributed what has happened to him, but not how he felt or what his concerns were. He swaps places with participant 20.

Participant 16 *[addressing Amanda]:* What causes cancer? Is there a cure for cancer?

[The group agrees that this is a good question. There is some discussion about it.

Irene: Participant 16, is there anything else Jim would like to say to the doctor?

Participant 16: I didn't like it when my friend and my brother died of cancer.

Reflecting on the role play with the research team afterwards

Amanda: I liked the bit when I did the role play. I think that was really good. When Irene just asked the group what they wanted to talk to the doctor about, nobody said anything. But then they wanted to have a go at the role play and all their questions came out.

Gary: I think it would have been harder if Niki or Irene had acted as the doctor. It was easier for them to talk to us. They felt relaxed. They felt they could talk to Amanda.

9.10 Easy-read summary: Feedback letter to participants



17 June 2011

Hello everyone

Do you remember when we came from St George's to meet you in the group?

We came to do a study.
It was a study about **“People with learning disabilities who have a relative or friend with cancer”**.

Now we want to tell you what we found out.



Irene



Gary



Amanda



Niki

This is what we did in the meetings:

- We played the name game.
- We talked about people's experiences.



- We showed you a made-up story about Jim.
His father has cancer.
He goes into hospital.



- We answered some of your questions.
- We did some acting.
- We voted for the best ideas.



1



This is what you said

Some people said "I was told".
Other people said "I was NOT told".

Lots of people felt they should have been told about the cancer.
They deserved to know like the rest of the family.

Coping with cancer

Many people remembered exactly what happened when someone had cancer.

People said:
"I saw my mum die. It was awful."

Many people had to look after their mum or dad or friend.

People said:
"I'm the man of the house now."



Understanding cancer

Many people had lots of questions.

They were not sure how someone can get cancer.

People asked: "Can you catch cancer?"
They said: "No jargon words please!"

Someone to talk to

It helped people a lot if they talked to someone about it.

But lots of people had nobody to talk to about it.

People said:
"My family didn't want to talk about it."



Voting



We showed you some pictures of what would help.

Everyone selected the five “top ideas”.

You voted for the best ideas.

You put the papers in voting boxes.

We opened the boxes.

We counted the votes.



This is what you voted for.

Here are your **TOP IDEAS** for what helps:



1. Someone to talk to about my feelings and worries.



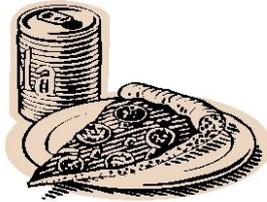
2. Someone to support the rest of my family.



3. My family, carers and doctors should tell me everything.

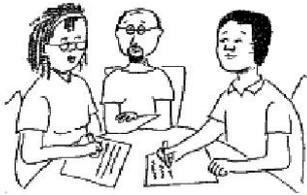


4. Someone I can ask questions about cancer.
A doctor or nurse.



We ended the meetings with a celebration.

What will we do next?



You thought of lots of things that could help people with learning disabilities who have a relative or friend with cancer.

We will write it all down and put it in a magazine.



We will talk about what you said to lots of people.
We will talk to doctors and nurses.
We will tell them what they can do better.

You did a wonderful job.

Thank you very much!



Irene Tuffrey-Wijne



Gary Butler



Amanda Cresswell



Niki Giatras