

National Audit Office

**Patient and Carer
experiences regarding
End of Life Care in
England**

Final Report

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England**

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This report takes into account the particular instructions and requirements of our client.

It is not intended for and should not be relied upon by any third party and no responsibility is undertaken to any third party

Job number

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Summary Table of Interviews and Focus Groups

Acknowledgements

Arup Project Management wishes to thank all the patients and carers who contributed their valuable views and suggestions regarding current end of life care services in England and how they might be improved.

In addition we would like to thank the following individuals and organisations who helped in the organisation of the focus groups and interviews:

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Executive Summary

Background

Each year around 500,000 people die in England, of whom almost two thirds are aged over 75 years. Of these, around a third are sudden or unexpected deaths as a result of an accident or heart attack. However a large majority of deaths follow a period of chronic illness such as cancer, stroke, heart disease, chronic respiratory disease, neurological disease or dementia. With these conditions, the patient's experience can be improved if good end of life care is in place.

End of life care is care that helps all those with advanced, progressive, incurable illness to live as well as possible until they die. It enables the supportive and palliative care needs of both patients and family to be identified and met throughout the last phase of life and into bereavement. It includes management of pain and other symptoms and provision of psychological, social, spiritual and practical support¹

Effective end of life care should aim to give people a "good death". Whilst there is no formal definition of what a good death is, for many this would involve:

- Being treated as an individual, with dignity and respect;
- Being without pain and other symptoms;
- Being in familiar surroundings; and
- Being in the company of close family and friends².

End of life care can be provided in a number of settings, including care homes, hospices and the patient's home. However, currently most deaths occur in hospital settings. Although some people do die as they would have wished, others may experience unnecessary pain and other symptoms or are not treated with dignity and respect.

The 2001 census established that there were 5.2 million people in England and Wales providing some form of informal care to a family member or friend. People providing informal care are often older people with health needs of their own. It is important to take the needs of carers into account when considering end of life care. Studies have shown that currently not all carers receive the Carers Assessment to which they are entitled and that the additional burden of care can put extra pressure on individual's physical and mental health and well being.

The NHS Cancer Plan³ and the majority of the National Service Frameworks emphasised the importance of palliative or end of life care. In 2004, NHS further built on its commitment to improving care by establishing an End of Life Care Programme which has encouraged the local adoption and development of end of life care models^{4,5,6}. The Department of Health produced an End of Life Care Strategy which was published in July 2008.

¹ National Council for Palliative Care 2006

² Department of Health (2007) End of Life Care Strategy for Adults Emerging Themes

³ Department of Health (2000) NHS Cancer Plan

⁴ Gold Standards Framework (GSF)

⁵ Liverpool Care Pathway for the Dying Patient (LCP)

⁶ Preferred Priorities for Care (PPC)

Terms of reference

The National Audit Office (NAO) commissioned Arup Project Management (Arup) to undertake a specific piece of work to obtain the views of adults identified as approaching the end of their life and those of carers of adults who are dying (or have recently died) on their experiences of end of life care in England. The objectives for the study were to identify:

- the main issues affecting people who have been diagnosed as being at the end of their lives and their carers;
- the practical changes that could be made to bring improvements to the lives of such people;
- the impact that such changes could have both on the lives of people who have been diagnosed as being at the end of their lives, and their carers.

The findings from this study will be used by the NAO together with information from other sources of data regarding end of life care that are currently being collected. This will enable a detailed report to be written by the NAO which will detail recommendations regarding how services for people who have been diagnosed as approaching the end of their life and their carers may be improved. It is expected that these recommendations will sit alongside the End of Life Strategy published by the Department of Health in July 2008.

In order to achieve the specified terms of reference, Arup worked closely with the NAO End of Life Care Study Team, adopting a qualitative paradigm for the purposes of this study. This investigation used both focus groups and semi-structured interviews. This agreed approach has enabled us to provide an in-depth exploration of the varying agendas and priorities of the participants and enabled holistic analysis to take place.

In total four focus groups and twelve semi-structured interviews were organised and conducted. Two focus groups were conducted with patients and two focus groups were conducted with bereaved carers. Five interviews were conducted with patients, three interviews with current carers, three interviews with bereaved carers and one with a patient and their main carer.

All focus groups and interviews took place between 22nd May and 11th June 2008. The fieldwork was facilitated by Pam Turpin and Rebekah Lane from Arup.

Summary Findings

The following paragraphs of this Executive Summary provide summary findings by the terms of reference for this project.

Our discussions with patients and carers highlighted both negative and positive issues around current end of life care practice. The negative items raised outweighed the positive. Negative issues raised included equity of access to services, many participants felt that the distribution of end of life care services and support was not equitable or consistent across all disease groups. In particular, carers of patients who had extreme frailty or were experiencing dementia often felt that their needs were treated differently from those with cancer. Positive reports included how much some carers appreciated receiving comprehensive support by their local primary care team. This had allowed their loved one to die at home surrounded by family and friends.

In reviewing the findings, it is important to note that they provide an 'insight' into the views and opinion of a small number of people experiencing end of life care in England. Therefore the findings and recommendations detailed throughout this report may not be representative of the views of all people experiencing end of life care services. It is suggested that the findings and recommendations contained within this report should be augmented with the wider programme of research currently being undertaken by the NAO.

The main issues affecting patients and carers experiencing end of life care services

This section summarises the issues most commonly identified by participants as requiring priority action.

Patients

- Lack of flexibility of services was highlighted, particularly around home care. Patients explained that often their daily activities were tied around agency staff rotas and working day.
- Patients should be fully supported in their particular choice of their preferred place of care. It was important for health and social care professionals – both policy makers and care staff – not to assume that everyone wishes to die at home.
- Improvements need to be made regarding the transfer of information across multiple care organisations, departments and professional boundaries.
- Counselling services should be easy to access. Patients often felt the need to talk to a third party outside of the family about their feelings and concerns for the future.

Carers

- There is poor integration and lack of cohesion between services.
- Lack of dignity and respect was highlighted. Negative experiences were reported regarding GP receptionist attitudes, the continuing use of mixed wards and insensitive treatment in hospital settings at time of death.
- The need for better training was highlighted particularly around the quality and level of experience of home care workers.
- Difficulties were highlighted around applying for financial benefits.

Practical changes that could be made to bring improvements to end of life care.

A number of practical changes were outlined by participants that would improve end of life care for both patients and carers. These included:

- Improvements in equity and consistency of access to services across all disease groups;
- Access to high quality respite care should be available to all individuals receiving end of life care services;
- Training, particularly around dignity and respect at end of life care should be made compulsory for all health and social care staff, including GP receptionists;
- Improved access to carer assessments;
- The removal of all mixed sex wards should happen at the earliest opportunity;
- An increase in permanent nursing staff on hospital wards in order to improve continuity of care;
- More information should be made available regarding accessing direct payments;
- One key contact for patients and carers to access information and support regarding their specific needs;
- Improvements in the availability of electric wheelchair provision;

- Improvements in Primary Care Trust (PCT) procedures regarding reviewing access to life-prolonging drug therapies;
- Improved information provision including information packs containing health and social care information, a single point of contact and mentoring service for patients and carers; and
- Easy access to counselling for both patients and carers.

Areas of change and why

Table One below demonstrates (with direct quotes provided alongside) a number of areas identified for change and includes examples of why changes are necessary to improve end of life care.

Area of change and why	
Areas for practical change	Patient or carer quote
Improvements in equity and consistency of access to services across all disease groups	<i>"He received a different level of care in my opinion. It actually made me feel that he was a second class citizen. It actually made me feel that he wasn't as important as someone with cancer." (Bereaved carer)</i>
Access to high quality respite care should be available to all individuals receiving end of life care services	<i>"My problem was respite 100%. ...They said give it a few days...I went down there and it was at half past twelve and he was in bed and he had his breakfast by the side of him. He had about three days growth [of beard], the room smelt terrible and there was all discarded clothes and everything. I queried it "I said when I came you showed me a laundry". She said 'Yes but you never asked for the laundry"... when we took his sock off he had a friction blister that went down to the heel and down the instep. They said they'd never noticed it." (Bereaved carer of patient with Parkinson's Disease)</i>
Training, particularly around dignity and respect at end of life care should be made compulsory for all health and social care staff, including GP receptionists.	<i>"..getting through a barrage of battleaxes on reception who say things like 'no you can't have a flu job' or 'no you can't see the GP, he's busy for the next six weeks' or whatever and you have to break confidentially by constantly telling people who you don't know your medical history in order to get anything." (Patient with breast cancer)</i>
Improved access to carer assessments	<i>"I never got a carers assessment. Now I don't know if that was because I didn't live with him or because I was the daughter in law?.... Perhaps if I had been offered a carers assessment, I wouldn't have had a breakdown." (Bereaved carer of patient with dementia)</i>
Removal of mixed sex wards	<i>"Can I add one thing about dignity? There can never be any dignity in a mixed ward. Which is what you have at the moment. Because with the best will in the world you go and visit somebody and as you are walking through like where my wife</i>

	<i>was you had patients with mental illness as well as physical illness and you could go in some days and there would be some poor old gentleman kicked all his covers off and he's lying there like the day he was born. Ladies used to go out to the toilet. They would put a robe round them nobody ever bother to tie them up and there they are walking out there for everyone to look at them. And to me, in wards like that, there is no dignity at all." (Bereaved carer of patient with stroke)</i>
Increase of permanent staff on acute wards	<i>"If the hospital had been like my wife's GP it would have been great but you've got too many agency staff that when you complain they turn round and say to me "I'm not particularly bothered I can leave here and get another job tomorrow." (Bereaved carer of patient with emphysema and heart failure)</i>
Improved flexibility of care (using direct payments)	<i>"I was having the night nurses calling in but it was difficult to contact them if you didn't need them because you had to go through some agency and you had to give them the address and telephone number of your GP and really all you wanted to do was say 'I'm not going to be in tonight so please don't get the emergency services to knock the door down. There didn't seem to be a way of actually contacting them directly. It's like today, if I want a nurse when I get home, say I want a comfort break; I would have had to book before nine o'clock this morning because they have a rota. They don't take bookings after four o'clock and the night nurses don't start until six o'clock." (Patient with MND).</i>
One key contact for patients and carers to access information and support regarding their specific needs	<i>"[Name] has got different illnesses and we are at different departments throughout the hospital. Each department is very good but we can't seem to get anyone that knows his case from beginning to end to be able to give us a prognosis. The doctor at the Macmillan's has been trying to do it but he can't get all the paperwork together because there are four different people." (Current carer of patient with cancer)</i>
Improvements in the availability of electric wheelchair provision	<i>"I had all that support, the medical site, fine, but the wheelchair thing... We tried for a wheelchair. We had a pushy wheelchair but [name] was six foot two and where I live it's a hill everywhere...and although I am quite big my hands are small – can't do it." (Bereaved carer of patient with renal failure)</i>
Improvements in Primary Care Trust procedures regarding reviewing access to life-prolonging drug therapies	<i>"The application was dealt by what they call a virtual panel. Over four days, two of which were a weekend and I can't imagine that those four people spoke to each other over a Saturday and Sunday...I've discovered they didn't even speak to my oncologist; they didn't speak to me, there was</i>

	<i>not an oncologist on the panel, there was no independent voice on that panel to speak to me and I feel they just dealt with my case by a cursory glance, no she's not having that drug, end of story. At a time when I should be enjoying every last minute, I am having to fight for a drug ..."</i> (Patient with cancer)
Improved information provision including information packs containing health and social care information, a single point of contact of advice and support and mentoring service for patients and carers	<i>"I had a suction machine, but we didn't know how to use it...I had to fit it all up ...but we still didn't know how to use it. How far to put the tube in, how long to leave it in for...There were all these bits and pieces and you would look at them and think what the hell am I supposed to do with that lot? They gave us a whole box of this piping. Then they gave us those long tubes and the little tubes, this that and the other and I thought, you have given me all this stuff, how do I use it? So in the end we just threw it all away. Some of it we took back to the hospital and some of it we threw away."</i> (Patient with COPD)
Easy access to counselling for both patients and carers	<i>"I got to the stage where there was no one I could talk to that wasn't personally involved with me. I felt as if I was protecting them. Does that make sense?"</i> (Patient with cancer)

Table One

Areas of change and how this would make a positive impact

Table Two below demonstrates a number of areas identified for change. Direct quotes from participants highlight how such changes in practice would make in a positive impact on quality of care.

Area of change and how this would make a positive impact	
Areas for practical change	Patient or carer quote
Improvement in service integration	<i>"at the MND clinic, they do that...like if I see the dietician and he suggests a supplement then the next thing it is coming from the GP via the local pharmacy. I have a team of therapists, physiotherapist, occupational therapists who I can see and they will relate back to the neuro team and they will come and visit me with the item which they have suggested or come and see what the problem is at home so they are constantly interacting."</i> (Patient with MND)
Access to high quality respite care should be available to all individuals receiving end of life care services	<i>"I call this my ten star hotel. As soon as they know that I am coming it's arranged that I have a special bed that helps prevent pressure sores. They know that I can't put my things away, so they arrange all that. They find out the state that I am in straight away because the doctor comes to see me."</i> (Patient with MS)

Comprehensive home support to patients and their carers	<i>“...the community nurses were brilliant because they thought of everything he needed – electric bed, things like his pills he was on about twenty five pills on a morning and then at three other times in the day it was getting quite confusing so she got a ..great big box in sections...that was brilliant. Practical things like that. ...She said if you need more help you have just got to ask...so anything we wanted... from the doctor’s surgery but she did it all.” (Bereaved carer of patient with renal failure)</i>
More information about accessing direct payment benefits	<i>“We are on direct payments so my husband can go for his respite every six weeks. When he goes off and does his own thing....I have a carer that lives just around the corner from us and I employ her and she comes in and does what I want her to do. I find it good for me. ...I could have had agency staff but I didn't want that because it is different people all the time. I just wanted one person that knows me and has one set of keys.” (Patient with MS)</i>
One key contact for patients and carers to access information and support regarding their specific needs	<i>“I mean you get the initial diagnosis, your head’s in a spin, you get loads of info and then there isn’t really a chance to follow it up. And when the dust is settled you think ‘oh my god what am I going do about X and Y and you probably do need a contact for that. So yes, if there was a place where they could be sure there was a contact available be it health or social care to help orient you through the morass of the system...if you had a fairy god mother like a MacMillan Nurse to come round and sit on your sofa for a couple hours, that would be wonderful.” (Patient with cancer)</i>
Improved information provision including information packs containing health and social care information, a single point of contact and mentoring service for patients and carers	<i>“It would have been really useful to have been given an information pack of where to go and what to do.” (Bereaved Carer of patient with dementia)</i>

Table Two

Recommendations for discussion and further consideration

Based on our research findings consideration should be given to the recommendations listed below. It should be noted that these are based on a small number of views and should therefore also be considered in light of the findings from the additional aspects of work being undertaken by the NAO into end of life care services.

Although the positive and negative information gleaned from the participants for this study is both powerful and, in some cases, moving and disturbing, they are examples of individual experiences of patients and carers who have accessed end of life care services. Without wider research and further discussion these findings and resultant recommendations should not be interpreted as being necessarily representative of all patients and carers experiences in relation to end of life care services in England.

Recommendations

1. Consideration should be given to improving local co-ordination and integration between health and social care providers of end of life care services.
2. Local Primary Care Teams should maintain a database of carers and ensure that individual carer support needs are assessed at regular intervals, including access to respite care, counselling and home care and support services.
3. High quality respite care should be made available to all individuals receiving end of life care services. Consider unannounced inspection visits to all care home facilities to ensure high standard of care.
4. Easy access to counselling should be available for both patients and carers, including bereavement counselling.
5. Training, particularly around issues of dignity and respect should be made compulsory for all health and social care staff, including GP receptionists.
6. Clear information in relation to the following areas should be made available through all health and social care staff: If possible, patients and carers should be given the name of a key contact who fully understands their specific needs. Information offered should include:
 - Practical advice regarding managing finances and applying for welfare entitlement;
 - Information on condition and progress and prognosis;
 - Information about community equipment, including wheelchair provision;
 - Information about local services, including an easy to access contact list for both medical and social care support services; and
 - Information regarding preparation of wills
7. Where possible permanent nursing staff on hospital wards should be increased in order to improve continuity of care.
8. PCTs should review their procedures for patient appeals regarding access to life-prolonging drug therapies

1 Background and terms of reference

1.1 Background

Each year around 500,000 people die in England, of whom almost two thirds are aged over 75 years. Of these deaths, around a third are sudden or un-expected as a result of an accident or heart attack. However a large majority of deaths follow a period of chronic illness such as cancer, stroke, heart disease, chronic respiratory disease, neurological disease or dementia. With these conditions, the patient's experience is improved if good end of life care is in place

End of life care, is care that helps all those with advanced, progressive, incurable illness to live as well as possible until they die. It enables the supportive and palliative care needs of both patients and family to be identified and met throughout the last phase of life and into bereavement. It includes management of pain and other symptoms and provision of psychological, social, spiritual and practical support⁷

Effective end of life care should aim to give people a "good death". Whilst there is no formal definition of what a good death is, for many this would involve:

- Being treated as an individual, with dignity and respect;
- Being without pain and other symptoms;
- Being in familiar surroundings; and
- Being in the company of close family and friends.⁸

End of life care can be provided in a number of settings, including care homes, hospices and the patient's home. However, currently most deaths occur in hospital settings. Although some people do die as they would have wished, others may experience unnecessary pain and other symptoms or are not treated with dignity and respect.

The 2001 census established that there were 5.2 million people in England and Wales providing some form of informal care to a family member or friend. People providing informal care are often older people with health needs of their own. It is important to take the needs of carers into account when considering end of life care as studies have shown that currently not all carers receive the Carers Assessment to which they are entitled and that the additional burden of care can put extra pressure on individual's physical and mental health and well being.

The NHS Cancer Plan⁹ and the majority of the National Service Frameworks emphasised the importance of palliative or end of life care. In 2004, NHS further built on its commitment to improving care by establishing an End of Life Care Programme which has encouraged the local adoption and development of end of life care models^{10,11,12}. The Programme is currently developing an End of Life Care Strategy which is due to be published in July 2008.

⁷ National Council for Palliative Care 2006

⁸ Department of Health (2007) End of Life Care Strategy for Adults Emerging Themes

⁹ Department of Health (2000) NHS Cancer Plan

¹⁰ Gold Standards Framework (GSF)

¹¹ Liverpool Care Pathway for the Dying Patient (LCP)

¹² Preferred Priorities for Care (PPC)

1.2 Terms of reference

The National Audit Office (NAO) commissioned Arup Project Management (Arup) to undertake a specific piece of work to obtain the views of adults identified as approaching the end of their lives and those of carers of adults who are dying (or have recently died) on their experiences of end of life care in England. The objectives for the study were to identify:

- the main issues affecting people who have been diagnosed as being at the end of their lives and their carers;
- the practical changes that could be made to bring improvements to the lives of such people;
- the impact that such changes could have both on the lives of people who have been diagnosed as being at the end of their lives, and their carers.

The findings from this study will be used by the NAO together with information from other sources of data regarding end of life care that are currently being collected. This will enable a detailed report to be written by the NAO which will detail recommendations regarding how services for people who have been diagnosed as approaching the end of their lives and that of their carers may be improved. It is expected that these recommendations will sit alongside the End of Life Strategy published by the Department of Health in July 2008.

2 Our approach

2.1 Overview of our approach

In order to achieve the specified terms of reference, Arup worked closely with the NAO End of Life Care Study Team, adopting a qualitative paradigm for the purposes of this study. Such methodology enables a versatile and rich approach allowing understanding and exploration of people's personal experiences and perceptions as they encounter, connect and live through situations. This investigation used both focus groups and semi-structured interviews. This dual approach enabled patients who were approaching the end of their lives and who were not well enough to attend focus group discussions to take part in the study to have their views heard and reported. This agreed approach enabled us to provide an in-depth exploration of the varying agendas and priorities of the participants and enabled holistic analysis to take place.

In total four focus groups and twelve semi-structured interviews were organised and conducted. Two focus groups were conducted with patients and two focus groups were conducted with bereaved carers. Five interviews were conducted with patients, three interviews with current carers, three interviews with bereaved carers and one with a patient and their main carer. **Appendix A** provides a detailed summary of the participant subgroup breakdown across location, method (focus/group/interview), number of participants and gender.

2.2 Ethical Considerations

This piece of work gathered data from a particularly vulnerable client group. Because of our concerns regarding the sensitive nature of this work, Arup took advice from the NAO regarding the ethical considerations required by them. Under their direction, this study has therefore complied with the Research Market Council's Code of Conduct and Confidentiality Guidance.

In addition, it was recognised that some participants may have both cognitive, sensory and mobility impairments which might result in challenges in gaining informed consent in some cases. In line with the participatory nature of this research, it was important that consent was obtained before any participant's views were sought. Arup therefore sought advice from the NAO and the 'gatekeeper' organisations that assisted in the identification of potential participants. It was agreed that involvement of any participants in the study should operate on a basis of 'process consent'. This involved treating consent as an ongoing process and not a one-off decision. A record was kept on how consent was obtained from all contributors throughout the study period.

2.3 Study documentation design

All documentation used during the study was discussed with and approved by the NAO. This included:

- Topic Guide;
- Information Sheet;
- Letter to participants;
- Reply slip;
- Consent Form.

All documentation was designed for use at both the focus groups and interviews and tailored to meet the needs of either patient, current or bereaved carers. Following approval

by the NAO, these were sent to the agreed Gatekeeper Organisations for final approval and circulation to potential participants.

2.4 Recruitment

A purposive sampling strategy was used to identify all participants for the study¹³. This approach uses a deliberate non-random method of sampling, aimed at identifying a group of people with a particular characteristic.

The criteria for inclusion for participants was that they had had either a clinical diagnosis that they were approaching the end of their lives or that they were (or had recently been) a carer or supporter of such an individual. The three trajectories of illness as documented by the World Health Organisation would be covered in this study, namely: cancer, organ system failure and dementia/frailty. In addition, efforts would be made to ensure a mixture of settings and socio-economic groups were considered.

Previous to the commencement of the study process, the NAO contacted a number of carer and palliative care organisations to ask if they would act as 'gatekeepers' in assisting Arup by identifying individuals who would be both willing and able to take part in the study. This form of snowball technique is particularly useful for hard to reach groups¹⁴ where a small number of people have direct access to the target population.

Following this initial approach by the NAO, an Arup facilitator approached each identified 'gatekeeper' to organise the logistics of each focus group or interview and advise them on the recruitment criteria required when inviting participants to attend.

Once potential participants had been identified, an introductory letter, information sheet and consent form describing the aims and objectives of the study were sent to each individual via each gatekeeper organisation. This initial contact aimed to reassure people about issues such as confidentiality, anonymity and data protection.

In total four focus groups and 12 semi-structured interviews were organised. These included: one focus group within the Sunderland area and three in London. Interviews were arranged in Kent, Peterborough, North Yorkshire and London. Approval of all locations was sought from the NAO prior to the recruitment of participants.

2.5 Fieldwork

All focus groups and interviews took place between 22nd May and 11th June 2008. The fieldwork was facilitated by Pam Turpin and Rebekah Lane from Arup.

Each focus group lasted approximately one and a half hours and varied in size from two to seven individuals participating at any one time. A member of the NAO study team also attended three of the focus groups and acted as an impartial observer of the process.

Most of the semi-structured interviews were conducted on a one-to-one basis. The exceptions were one interview with a patient and their main carer, and one interview with two bereaved individuals who had jointly cared for a family member. The interviews lasted approximately one hour.

¹³ Descombe M (1998) The good researcher guide for smaller social research projects (Open University)

¹⁴ Krueger A & Casey M A (2000) Focus Groups (sage Publications)

2.5.1 Procedure

Participants were assured that their participation was voluntary, that they could end the interview session at any time and that their identity would be protected. Interviews took place at the individual's own home or at the gatekeeper organisation, ensuring at all times that they were conducted in secure and confidential surroundings. Discussions were tape-recorded following agreement with the participants. The interviews were guided by a semi-structured interview schedule devised from the topic guide, which consisted of a small number of open-ended questions. The topic guide was developed following initial discussions with the NAO and was slightly redefined after the first interview had taken place in order to reflect the discovery of additional areas of interest that emerged as a consequence of this initial interview. This is consistent with the recommendations for carrying out the grounded theory method¹⁵ because it allowed the facilitator or researcher the flexibility to 'continuously review' the process and offers the opportunity to further explore emerging areas of interest. As a result, the interview schedule was developed to focus on six key areas of interest:

- Service Provision and Integration;
- Preferred Place of Care;
- Relationships, Dignity and Respect;
- Information and Communication;
- Access to Support for Carers; and
- Other Support Needs

The interview style was non-directive and a process of reflecting and probing was employed. This method of interview meant that participants largely dictated the development and content of each interview or focus group. Questions were used as 'triggers' to encourage the participants to talk about their experiences and help to drive the shape of the interview. Once rapport and trust had been established the primary role of the interviewer was facilitating the disclosure of the interviewees' perspective.

Each tape was fully transcribed within 48 hours of the interview or focus group taking place. Interviews were transcribed by the study team and then checked for accuracy and that all personal references had been removed. A copy of these final interview transcripts were then supplied to the NAO for their information.

2.6 Analysis of data

Qualitative techniques were used in the analysis of data drawn from the discussions¹⁶. A computerised spreadsheet was developed which categorised participant's quotes in a framework around the issues identified within the topic guide. Before analysis took place, the following steps were taken to ensure that all material was well organised.

- A unique code number for reference purposes was given to each interview or focus group to ensure confidentiality was maintained.
- A back-up copy of all original material was made for use during analysis. All data was stored in a secure location and could only be accessed by the study team.
- The study team worked collaboratively to obtain agreement regarding the themes and relationships identified.

¹⁵ Silverman D (2001) *Interpreting Qualitative Data* (Sage Publications)

¹⁶ Krueger A & Casey M A (2000) *Focus Groups* (Sage Publications)

2.7 Structure of this report

The structure of this report hereafter is as follows:

- **Section 3** sets out the key findings of the research in relation to service provision and integration of end of life care services;
- **Section 4** sets out the key findings of the research in relation to preferred place of care;
- **Section 5** sets out the key findings of the research in relation to relationships, dignity and respect;
- **Section 6** sets out the key findings of the research in relation to information and communication;
- **Section 7** sets out the key findings of the research in relation to access to support for carers;
- **Section 8** sets out the key findings of the research in relation to other support needs;
- **Section 9** sets out the main issues that affect individuals approaching the end of their lives and their carers and their ideas regarding future changes/improvements;
- **Section 10** sets out recommendations for discussion and further consideration.

2.8 Disclaimer

It should be noted that this piece of qualitative study provides an 'insight' into the views and opinions of a small number of individuals experiencing end of life care services - 12 patients; 4 current carers and 12 bereaved carers.

Therefore the findings and recommendations detailed throughout this report may not be representative of the view of all people experiencing end of life care services within England. They are useful in providing insights into the experiences of a variety of individuals and should be considered and interpreted within that context. However, it is suggested that the findings and recommendations contained within this report should be augmented with the wider programme of research currently being undertaken by the NAO which aims to capture current issues regarding end of life care in England.

3 Key Findings – Service Provision and Integration

In this section of the report we explore the experiences of patients and carers regarding service provision and integration of services including equity and consistency of access to services; health and social care professionals involved in end of life care; respite care services; access to community equipment and medication.

3.1 Equity and consistency of access to services

3.1.1 Conditions

A number of patients and carers within the study felt that the distribution of services and support was not equitable or consistent across all disease groups. Patients suffering with cancer, or carers looking after patients with cancer had a very different experience of end of life services compared to those patients, and carers of patients, with other conditions such as dementia.

“He received a different level of care in my opinion. It actually made me feel that he was a second class citizen. It actually made me feel that he wasn’t as important as someone with cancer.” (Bereaved carer)

“My father had vascular dementia but actually died of cancer and he wasn’t getting any help with his vascular dementia...as soon as he got cancer and they could say when he was going die in a certain time... then all of a sudden bam bam he gets all these services, its incredible, then he dies very quickly.” (Bereaved carer)

Interestingly, several people expressed the difference in how conditions were treated in terms of whether a finite timescale could be attributed to the condition. Some people acknowledged that with certain conditions such as cancer it is easier to determine when the patient is entering the end stages of their life as opposed to conditions where deterioration in health can be gradual and extended over many years, such as dementia.

“...it was different for different conditions, as I have known people that have died from cancer and it is different, so it’s not an easy one that one – when are they going to die? When they have pneumonia and they look terrible, you know they are going to die but you don’t know when or how long they have got.” (Bereaved carer of patient with dementia)

3.1.2 Perceived inequalities of service provision

During the interviews and focus groups it became clear that participants from the same geographical area had had very different experiences of accessing end of life services within the community. People who had lived in a particular geographical area for a long period of time seemed able to access services they needed easier than those new to the area. This was particularly noticeable in patients with long term conditions who had established good relationships with their GP and local health and social care teams over a period of years.

“The doctor had known us all our lives – knew [name of patient]’s family history and his medical history – knew me – so it was more like a personal service really and the doctor knew of the state I was in as well.” (Bereaved carer of patient with renal failure)

“It was a new thing ... this community nursing ... They were so helpful and if I needed them I just rang them up.” (Bereaved carer of patient with renal failure)

In contrast, one carer who had moved to the same area to live just as her husband's health had suddenly deteriorated had struggled to find help.

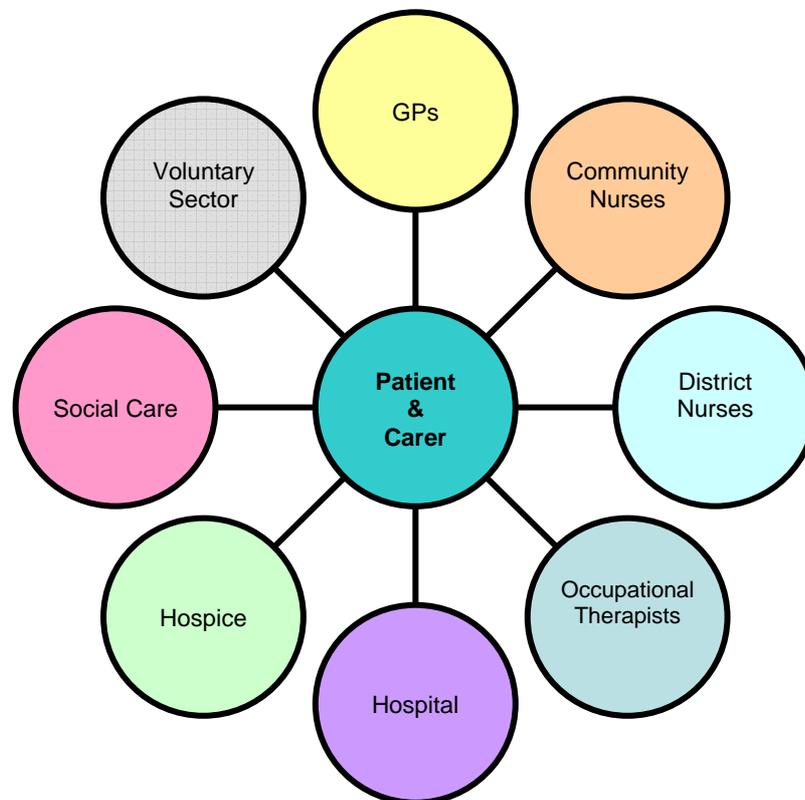
"I did everything. I had nothing. I was just getting to know about these things and I think [name] had just come to me this year to assess me because they thought I needed it." (Bereaved carer of patient with heart failure)

Similarly, a number of participants perceived that access to services was "a postcode lottery" and largely dependent on how local services were arranged, what initiatives were in place and what information was supplied by their GP.

"What seemed to be the problem is the GP was no longer quite switched on to the necessity to push all those other services – those other buttons – we are talking hospice, local hospitals for rehab care, we are talking MacMillan, flu jabs which I was denied ... a district nurse being obtained, the relevant signatures to all the benefits and of course local authority help with disability allowance.... Obviously we moved GPs." (Patient with Breast cancer)

3.2 Health and Social Care Professionals involved in end of life care services

Patients and carers accessed support from a myriad of health and social care professionals. Evidence of this is shown throughout Section 3 and illustrated diagrammatically below.



3.3 Primary Care

3.3.1 General Practitioner

In most cases, the GP was seen as a key individual by both patients and carers. In the majority of cases, carers and patients reported favourably both on the care they received and their relationship with their GP. This was particularly noticeable in people with long term conditions and their carers.

“Our relationship with our doctor was friends. He used to come in and have a laugh and a joke always because [name] knew what part of India he came from because he was out there and they used to really converse and they were friends.” (Bereaved carer of patient with Parkinson’s Disease)

“My own doctor that I am registered with, came to see me, he sat there and talked to me for about 45 minutes, which I found very useful.” (Patient with MS)

“If I am very, very depressed and I am not feeling well, if I saw my GP and he talked to me, I feel good, I feel better.” (Patient with heart failure and diabetes)

However, there were also a number of participants that expressed disappointment with the care, support and advice they received from their GP.

“My GP told me that I couldn’t have a MacMillan Nurse because I didn’t have secondary cancer which is in fact wrong. So there seems to be an issue there with GP guidelines so fortunately for me I was able to articulate stuff and do my research so I contacted MacMillan through their website and sorted that out and was contacted by [name of hospice].” (Patient with breast cancer)

“With the GP for example...I find it a bit difficult because of the way she might talk to me. She would talk to my father differently than she would talk to the daughter...maybe she doesn’t appreciate the fact that there is a secondary person...”(Current carer of patient with heart failure)

Dissatisfaction was particularly noticeable from carers of patients with dementia; often around the onset of the condition or the rate at which it was advancing.

“It shouldn’t have been down to me to raise the issue of dementia with the GP and it was me that asked them to do the dementia test, when he very clearly had no short term memoryIt shouldn’t be down to the patient or the carer to ask those questions you would want the GP to be able to pick up on that, particularly as he had been his GP for fifteen years.” (Bereaved carer of patient with dementia)

“I wouldn’t like to blame the GP, but I don’t think that he did as much as he could have done.” (Bereaved carer of patient with dementia)

3.3.2 Primary Care Team

Community nurses and district nurses were much appreciated, particularly by carers, for both the nursing and emotional support they gave. They were also seen as instrumental in liaising with social care and assisting in organising the provision of community equipment.

"...the community nurses were brilliant because they thought of everything he needed – electric bed, things like his pills he was on about twenty five pills on a morning and then at three other times in the day it was getting quite confusing so she got a ..great big box in sections...that was brilliant. Practical things like that. ...She said if you need more help you have just got to ask...so anything we wanted... from the doctor's surgery but she did it all." (Bereaved carer of patient with renal failure)

"The district nurses were excellent, I couldn't fault them." (Bereaved carer of patient with brain tumour)

However, dissatisfaction was mentioned regarding GP receptionists who in a number of cases were seen as a major barrier between patient, carer and the GP.

"they are the best gatekeepers in the world, doctor's receptionists." (Current carer of patient with dementia)

"...five weeks before my husband died he was put on pills in the hospital and I went in and asked the receptionist for his pills, this was on the Thursday. I couldn't have them until the Tuesday because it was Bank Holiday Monday. I said I was going to run out and my husband needs these and she said, the young girl said to me well Mrs [name] you'll have to go on an emergency list again!...and I walked out in tears and I said well don't worry about it, I'll get the doctor out on Monday as an emergency and I'll get the pills." (Bereaved carer of patient with heart failure)

"...getting through a barrage of battleaxes on reception who say things like 'no you can't have a flu job' or 'no you can't see the GP, he's busy for the next six weeks or whatever' and you have to break confidentially by constantly telling people who you don't know your medical history in order to get anything." (Patient with breast cancer)

3.4 Out of Hours Services

Patients and carers who had care packages in place, often used the community nurses for out of hour's assistance. Others reported that they called 999 rather than trying to access the out of hours GP service. Only one carer reported that he had used NHS Direct and was happy with the support he had received via the telephone

"I had to ring NHS Direct, they were pretty good, they didn't rush out but then I suppose its quite right that they shouldn't rush out on every occasion....but they were certainly partially reassuring shall we say, because when its...two or three in the morning you feel a bit alone and helpless anyway but at least there was somebody on the phone to talk to that said do this, do that whatever, so yeah I have only had to use them the once but they were there." (Current carer of patient with cancer)

Some participants were uncomfortable with the fact that when accessing the GP out of hour's services, they would be visited by a doctor who did not know anything about their condition.

"If you call the doctor out of hours you would get some Indian guy. I've got nothing against Indians but he is working nights and doesn't know who the hell you are." (patient with cancer)

"They don't know whether it matters or not. Whilst one's doctor who knows you – he knows if something is unimportant or knows if it actually does matter." (patient with COPD)

3.5 Hospital Care

Overall, participants' experience of hospital services appeared to be largely polarised across the study – they were either very good or very bad. The positive comments regarding such services tended to focus on the people with whom they had the most contact, such as their primary consultant. Positive experiences centred on the relationships that patients and carers had with members of the secondary care team.

"...he'd been into the Kidney Unit several times and it was brilliant, they really looked after him and got him better ...so he had a better life than he would have done previously." (Bereaved carer of patient with renal failure)

"The Doctor refers me to go to [name of hospital] ...so because the doctor looking after me its very good and they look after me so that all the sickness that I have, they are keeping me alive. I am staying alive because they look after me." (Patient with heart failure and diabetes)

"The treatment that I've had and the care at the hospital was absolutely wonderful." (Patient with cancer)

In contrast to these experiences, other individuals in the study expressed very negative feelings towards their treatment and interaction with acute services (See Section 5: Relationships, Dignity and Respect). However, in these cases the dissatisfaction extended beyond personal relationships with key members of staff, to issues relating to the quality and consistency of the care experienced, equipment and food.

"We phoned the ambulance and got him up to the hospital. They said right we are going to ward him....gets him in there, the beds are too high, got no lower beds for him to get in, the chairs that they had at the side, can't get in that because they are so tiny and there are no recliners and they said oh well he will have to sleep in his wheelchair all night. So he said right that's it I am off and we came home." (Current carer of patient with COPD)

"I couldn't use the bell push to call them [nurses] when I needed them because I hadn't got enough strength in my fingers, they had got a serious problem with bell pushes with people of limited ability, but they didn't do anything about that. My meals were brought to me and because my surname begins with a B, they brought it to me first because it was done in alphabetical order. So when the young man who was dealing out the meals I found out that he would hand out all the meals and the hot drinks and then come to me so mine was cold." (Patient with MS)

One particular area of concern that was brought up by a number of participants was the number of agency staff. They felt this often resulted in a poor standard of care due to lack of commitment and in some cases not being able to discuss issues with them fully because staff are unable to speak English.

"If the hospital had been like my wife's GP it would have been great but you've got too many agency staff that when you complain they turn round and say to me "I'm not particularly bothered I can leave here and get another job tomorrow." (Bereaved carer of patient with emphysema and heart failure)

"Well, in the hospital there is always different agency nurses....you never have the same one twice." (Current carer of patient with COPD)

"...there is a need to have decent, fully trained staff that are training in this country to this country's standards not agency staff that can't even speak English." (Bereaved carer of patient with COPD)

3.6 Personal and Social Care Services

Overall, participants' experience of social care was poor. A number of people spoke of their frustration, anger and despair at how they were treated by social services.

"I was a full time carer for my wife who suffered from emphysema and heart problems and I cared for her for about 13 years. And in all that time I never found any help from social services or anybody else." (Bereaved carer)

"I realised that I couldn't trust social services to do what they said they would do. It's OK a hospital social worker saying well it's the community health team's responsibility to do this that and the other, but they weren't dealing with the day to day problems of them not turning up." (Current carer)

Participants in the study expressed concern about the quality, training and level of experience of the care workers they had encountered. Many felt that they were not able to understand or meet patient needs. The service was perceived as unreliable, process driven and poorly resourced.

"..I've had social services 2 or 3 times over the years and I've had others. Some of them are totally useless. Untrained people.... A lot of the times it annoys me and so I ring them up and complain. But they never do anything about the complaints." (Patient with MS)

"I would organise home help to come in four times a day ... they would check things but not tell me if things weren't right, ...it was a nightmare really, a total nightmare." (Bereaved carer of patient with dementia.)

"It was just a disaster from day one in things that didn't work....carers not coming in when they were due to so at one point I went away for two days to a niece's christening and I came back to find my dad stuck in bed and had been for a full twenty-four hours and obviously he had not been able to get out to use the toilet or anything so he was sitting in his own filth." (Current carer of patient with dementia)

"I was absolutely appalled by the fact they are just not trained. I remember coming home one day and there was this, well I would call her a girl, she was about 16 years old – she had no training in dementia and I arrived ...and he said 'I'm so cold' and I took his coat off and all he was wearing was a pair of socks and underpants and she was supposed to be caring for him...she was just completely out of her depth. ...and if that's the quality of home help coming in then...I don't know how widespread it is, I can only talk from my experience." (Bereaved carer of patient with dementia)

3.7 Respite Care Services

Participants were asked if they had accessed respite care services. The majority of patients with cancer reported that they were receiving respite via their local hospice whilst provision for people with other health conditions was usually in care home facilities.

3.7.1 Hospice Care

Participants' experiences of hospice care were extremely positive and complimentary. Many saw these services as an essential and central part of end of life care. These services were perceived as providing holistic, patient and carer centred care. A combination of emotional, financial, legal and medical advice was provided. However, the most noted benefit of these services was the opportunity to meet other people in similar situations. The ability to share and learn from others who could appreciate and understand the reality of end of life was regarded as extremely valuable by many. It provided a crucial social outlet that allowed individuals to be accepted and included.

"I do go to the hospice for pampering. I am having the Bowen Technique, I've had it before. I've had reflexology up at the hospice and they also do massage. I think they just call it day therapy whereas I have been up there in the morning one day a week and I have a bit of pampering in the morning, the reflexology, the massage whatever, then there's lunch and then we do a bit of arts and crafts or what not in the afternoon....I made friends with lots of people." (Patient with cancer)

"I call this my ten star hotel. As soon as they know that I am coming it's arranged that I have a special bed that helps prevent pressure sores. They know that I can't put my things away, so they arrange all that. They find out the state that I am in straight away because the doctor comes to see me." (Patient with MS)

"All the staff and the volunteers are the backbone of this place.... they are the unseen heroes, even down to somebody giving you a cup of tea...I am even getting my council tax sorted out through here because I am here three times a week." (Patient with cancer)

Interestingly, a number of individuals did acknowledge that they had originally resisted any association with a hospice due to a preconceived perception of what a hospice was and what it provided as a service.

"When the word hospice comes into mind....well when you were put in there, you never came out did you. Then I said to her I have always had a thing in life; try it once if you don't like it, don't do it again. So I said to her I will come down and if I don't like it I won't come again. Now I can't wait! I go every Wednesday, it's brilliant." (Patient with cancer)

"This is how I come to be here, because one of the ladies who is with the Macmillan's suggested that I come here, like the word alone – 'hospice' you know – I asked why do you want to send me to a hospice and she said just to meet other people. I come here and I have been here for three years now and I have met some wonderful people." (Patient with cancer)

"I said no, when she mentioned the name hospice...like hospices are synonymous with death as far as I was concerned....then when I came here it just blew the cobwebs off ..I do art on Monday, exercise on Tuesday and I do Yoga on a Thursday; where else could I get that?" (Patient with cancer)

It should be noted that in order to present a fair and balanced assessment of the data that was collected, it must be acknowledged that the majority of patients that took part in the study were accessed via palliative care organisations and therefore had easy access to hospice services.

3.7.2 Respite within nursing/care homes

Discussions with many of the carers revealed that patients with other conditions, particularly older people with extreme frailty or dementia, could only access respite provision via care homes and that the standard of care was reported as poor or inadequate.

"I walked in and you could hear my dad shouting for help.Dad was saying that he wanted to go to the toilet. So I went and told someone that he wanted the toilet and they said 'he would have to bloody wait, he is being a right nuisance'...Eventually someone came in and while they were transferring from the chair to a commode, he just let rip and it went everywhere. Eventually they got him in to the bathroom, sorted him out...the faeces was still up the wall, all over the carpet, they didn't bother clearing it up. They just dragged dad straight through it all and plonked him onto his bed! I came out of there and phoned my eldest brother and he told me to leave it because mum needed the break." (Bereaved carer of patient with dementia)

"My problem was respite 100%. They said give it a few days...I went down there and it was at half past twelve and he was in bed and he had his breakfast by the side of him. He had about three days growth [of beard], the room smelt terrible and there was all discarded clothes and everything. I queried it "I said when I came you showed me a laundry". She said 'Yes but you never asked for the laundry"... when we took his sock off he had a friction blister that went down to the heel and down the instep. They said they'd never noticed it." (Bereaved carer of patient with Parkinson's Disease)

3.8 Voluntary Sector

Positive feedback was also received from participants, particularly carers, regarding the importance of the voluntary sector. Such organisations were seen to offer both emotional support and much needed practical assistance such as helping people fill in forms to access welfare benefits or community equipment; to providing volunteers to support carers in their caring role.

"Another problem I found was the shopping, when there is only one person and you've got somebody you really can't leave...after a while I found out that you could go to Age Concern and they sent a lady, who was very good because you hesitate when it's once a week to keep asking people ."(Bereaved carer of patient with brain tumour)

"I feel better if I am talking to him [Carer Centre Support Officer]. ... He is very gentle to talk to and he always tries to help you." (Patient with heart failure)

"..I can't knock the Parkinson's Association at all. They used to come and give an assessment every six months and the Parkinson's nurse also gave me her home number and mobile number so if anything unforeseen came up I could ring." (Bereaved carer of patient with Parkinson's Disease)

"We belong to Beating Bowel Cancer Charity...they have been very supportive." (Carer of patient with cancer)

3.9 Service Integration

The study revealed that a large number of the participants felt that there was little integration among services that were involved in their care. Many felt that services were disjointed and lacked a “common sense” approach to patient care. People perceived services as unresponsive to their needs and expressed frustration at the lack of cohesion between services.

“The whole system is not integrated, housing, social care, health, it all needs a radical rethink.” (Current carer of a patient with dementia)

“I said to Dr X, those nurses you’ve got coming round and he said I don’t know anything about that, he said we don’t talk about that. They are two separate departments.” (Current carer of patient with COPD)

“[Name] has got different illnesses and we are at different departments throughout the hospital. Each department is very good but we can’t seem to get anyone that knows his case from beginning to end to be able to give us a prognosis. The doctor at the Macmillan’s has been trying to do it but he can’t get all the paperwork together because there are four different people.” (Current carer of patient with cancer)

“It’s time to go home [from hospital] which is on Christmas Eve. They have done this package for me. People are going to come out to visit me, I am going to get meals on wheels and get this, that and the other. Nothing happened until February.... I am at the pity of all my neighbours, because they are bringing me food in, there’s nothing in the fridge and I can’t go shopping because I am so breathless.” (Patient with cancer)

However, an example was given of good communication which had made a positive impact on the quality of care received by one patient.

“at the MND clinic, they do that...like if I see the dietician and he suggests a supplement then the next thing it is coming from the GP via the local pharmacy. I have a team of therapists, physiotherapist, occupational therapists who I can see and they will relate back to the neuro team and they will come and visit me with the item which they have suggested or come and see what the problem is at home so they are constantly interacting.” (Patient with MND)

A number of individuals expressed a desire to have one main point of contact to signpost and support them through their end of life process. Carers expressed the need for this in terms of a mentor, to assist them with the practical arrangements and preparations while patients referred to a single point of contact to signpost and support them with the management of their illness.

“I would like to talk to just one person who can say ‘right this is your situation, this is what you are going through and everything’. At the end of the day I just want to know what’s happening but nobody can tell me.” (Patient with cancer)

“I think there should be someone like [name of carer centre worker] as a mentor to offer an overall service and I think that should be readily available.” (Current carer of patient with heart failure)

Patients suffering with cancer were extremely positive about the care and support they were offered by Macmillan Nurses. For these patients they provided essential practical and emotional support. In each interview with a cancer patient, the Macmillan Nurse was highlighted as their first point of contact if they had a worry or a problem.

"I would go to [name] and I do. [Name] is my Macmillan nurse from the hospice.... She is just the best." (Patient with cancer)

Patients described their contact with their Macmillan Nurses as frequent, open and easily accessible. The ability for individuals to contact someone directly, who had an awareness and appreciation for the specific detail of the individual's condition, provided a level of comfort and security for both carer and patient.

"I know I could see her every week if I needed to, she's at the end of the phone whenever I need her and she will be here within an hour if I needed her to be. But even speaking to her on the phone will lift me up." (Patient with cancer)

Individuals appeared to appreciate and value the personalised and tailored care that they received from the Macmillan Nurses. The experience of having a single point of contact was also mirrored by a bereaved carer who had accessed a community nursing scheme in Sunderland.

"It was a new thing in Sunderland, this community nursing and I thought it was quite intrusive at first – a funny reaction – because I had just finished work and my son had been doing the blood tests for the diabetes etc and the medication and everything. I remember I had gone up to the chemist and I came back and these two nurses were in my cupboard downstairs which is a glory hole of rubbish. I thought my goodness what are they doing in that cupboard, especially that cupboard, they could have picked another cupboard and I was a bit put out about it at first. Anyway they said who they were and they were the best friends we ever had. They were so helpful and if I needed them I just rang them up." (Bereaved Carer of patient with renal failure).

3.10 Access to community equipment

Many participants advised that they had to purchase equipment such as stair lifts themselves at a cost of between £2,000 and £6,000. However, it should be noted that a number of these individuals were living with long term conditions and had obtained this equipment some years previously.

Of those individuals needing this equipment as part of end of life care, the most common items supplied were special mattresses to prevent pressure sores, bed hoists, and electric bath lifts and hand rails, although some individuals were still having difficulty in obtaining equipment that fully met their needs.

"...I cannot raise my legs to get in the bathtub because it is too high... yes they give me that thing you can press up and down but its very heavy and I think I am not safe because when you press to go down its quick and my leg is terrible....sometimes I feel depressed because I always want to have a shower. I want to always clean myself because I am old. I am seventy-five and I don't want to be smelly when somebody is injecting me or something like that." (Patient with heart failure and diabetes)

One area of particular concern was the inability to access electric wheelchairs. Many carers were older people and had health concerns of their own and found it difficult to push a wheelchair any distance. This often meant that the individual they were caring for was essentially housebound unless a younger or stronger member of the family was available to assist them.

"I was getting older and I couldn't manage the wheelchair." (Bereaved carer of patient with heart failure)

"I had all that support, the medical side, fine, but the wheelchair thing... We tried for a wheelchair. We had a pushy wheelchair but [name] was six foot two and where I live it's a hill everywhere...and although I am quite big my hands are small – can't do it." (Bereaved carer of patient with renal failure)

"The thing is my pushchair, my wheelchair, if nobody push me how can I go out? ...so I said to [name] because they ask me and I said I want a little bit of electric something like that. My husband walking with me. I could use the electric one quite easily. That's what I want. I could go in the garden and look around there. My husband cannot manage to push me." (Patient with heart failure)

One patient with COPD highlighted that her PCT had moved away from local delivery systems which had resulted in the late delivery of vital oxygen supplies she needed to use at all times to keep her alive.

"They have taken away the supply from the chemists and the government gave it to companies with a monopoly over a certain area, so you have to deal with everyone and if I want something else they will say 'oh yes we will come' and I have to say there is no room can you give me a day when you will come – 'well we will if we can' – They were forever not turning up and it was a real problem, while beforehand the chemist only had to look after a few people and now the company looks after over a thousand people spread out over a huge distance. They have lost that personal touch; they cannot be as efficient, so people like me are left with one tank left, who knows what's going to happen when that ran out." (Patient with COPD)

3.11 Access to medication

A number of participants advised they had a very good relationship with their local pharmacist who would supply home delivery if needed.

"One of the things about the chemist is if there is something there and we haven't been in to get it, one of the girls lives around the corner and she brings it ..." (Carer of patient with COPD)

Dossett Boxes were often supplied to people who took a large number of tablets each day helping them manage their medication safely.

"They were giving it to him all loose but now they give it to him in the dossett boxes once a month. That way I know I can't run out of tablets when they are like this and [name] knows that I keep the one that I am using underneath there and he can just go to it and take out the section that he needs." (Current carer of patient with COPD)

However, one carer described the problems she had experienced obtaining medicines out of hours.

"In order to get the prescription she [nurse] needed a doctor's signature...I had to do it, so I had to go and leave her [patient], go to the NHS Walk-In Centre which is all time and then the nearest chemist... and I can't tell you when I was driving along there I was in such a tizzy. I had to leave her on her own, there was nobody around, it was a weekend and there was nobody I could think I could call on and I thought this was dreadful that you have to actually go out and do this. I thought that was one of the worst things and I imagine a few people must come up against this." (Bereaved Carer of patient with brain tumour)

Two patients with cancer had been refused further life prolonging medication. One was resigned to this and had accepted that this would hasten his death.

"I can't have more chemotherapy, if I could it would prolong my life. It's a financial thing – it costs about £5,000 a pop for chemo. At first there was a bit of anger, but there is nothing I could do about it really so what the hell, what am I going to do making myself sick through anger. It's a financial thing and that's that." (Patient with cancer)

However, the second patient was appealing to her PCT. She was particularly angry at the PCT's impersonal nature of reaching their decision by using a 'virtual panel' and not allowing her views to be taken into account.

"The application was dealt by what they call a virtual panel. Over four days, two of which were a weekend and I can't imagine that those four people spoke to each other over a Saturday and Sunday...I've discovered they didn't even speak to my oncologist; they didn't speak to me, there was not an oncologist on the panel, there was no independent voice on that panel to speak to me and I feel they just dealt with my case by a cursory glance, no she's not having that drug, end of story. At a time when I should be enjoying every last minute, I am having to fight for a drug ..." (Patient with cancer)

Another patient voiced her anger that people were not allowed to pay for certain drugs unless they agreed to pay for all their subsequent treatment.

"It makes me terribly, terribly angry when you read in the paper these days that you need a particular drug and your local PCT won't give you it unless you pay for it yourself. Then they turn round and say you've got to pay for all your treatment..." (Patient with COPD)

Section summary: Service Provision and Integration

Equity and consistency of access to services

- Participants felt that the distribution of services and support was not equitable or consistent across all disease groups.
- Some participants from the same geographical area had different experiences of accessing care.

Health and Social Care Professionals involved in end of life care services

- Patient and carers accessed support from a large number of different health and social care services.
- GPs are seen as key individuals by both patients and carers in the management of care and support.
- Community and district nurses were appreciated for their nursing and emotional support, particularly by carers.
- There was dissatisfaction by both patients and carers regarding the attitude of GP receptionists.

Out of Hours Services

- Community nurses or the emergency services were often used to access out of hours care.

Hospital Care

- Participants' experience of hospital services appeared to be either very good or very bad.
- Positive experiences centred on relationships whilst negative experiences related to the quality and consistency of care, equipment and food.

Personal and Social Care Services

- Overall, participants' experience of social care was poor.
- Specific concerns were voiced around the quality, training and level of experience of care workers.
- The service was perceived as unreliable, process driven and poorly resourced.

Hospice/Respite Care Services

- The majority of patients with cancer received respite via their local hospice.
- Hospice care was perceived as holistic and patient and carer centred.
- A number of individuals acknowledged that they had originally resisted any association with a hospice due to preconceived negative perceptions.
- Patients with other conditions, particularly extreme frailty or dementia accessed respite via care homes and the standard of care was reported as poor or inadequate.

Voluntary Sector

- Voluntary organisations were highly valued and seen to provide both emotional support and practical help.

Service Integration

- Services were perceived as unresponsive to patient and carer needs.
- Participants felt there was a lack of cohesion between services.

Access to community equipment

- The most common items supplied were special mattresses to prevent pressure sores, bed hoists, electric bath lifts and hand rails.
- Access to electric wheelchairs was poor.

Access to medicines

- Home delivery of medicines and medicine management using dossett boxes was appreciated.
- Withdrawing of life prolonging medication was reported.

4 Key Findings – Preferred Place of Care

In this section of the report we discuss people's preferred place of care and then explore their preferred place of death and the rationale for the choices made.

4.1 Preferred Place of Care

Participants were asked about their preferred place of care. For many people, this was their own home. It was noted that a key reason for this decision was often the support they received from their family and friends in familiar surroundings.

“Here at home. It’s because I have got my family support here, because the kids are good. My stepson lives with us and my step daughter turns up every now and again.” (Patient with cancer)

A number of people who lived alone also wished to be cared for at home and being moved into a care facility was a frightening thought and only something they would do with great reluctance.

“I live in council sheltered housing and my fear is that are continually saying, the sheltered housing officer, you should go into a care home. I feel there is a suspicion that I am not able to look after myself and they really want to get me out of their house into a home. It frightens me.” (Patient with cancer)

“One of the doctors wanted me to go into a nursing home and I don’t want that.” (Patient with MS)

4.2 Preferred place to die

A patient's preferred place to die appeared to be influenced by a number of factors. For some patients it was influenced by their past experiences of places, such as hospitals or hospices. For others it was based on the level of medical or personal support they would receive. For others it was centred around either, the fear of being alone or a burden it would place on their family. From our analysis, a patient's ability to choose where to die was deemed important to many as was the need to recognise that there were differences and variations in where people wanted to die. An individual's preferred place to die appeared to be a very personal and individualised choice.

“My actual desire is to die at home. It’s in my notes and the question is as it comes closer to the time, my carers have been very good and have been with me for a long time – but they are not always English speaking and so they are not always able to able to communicate what I want to say. I don’t think everyone is always actually listening to what the patient wants totally.” (Patient with cancer)

However, if their health deteriorated, a number of people, particularly those without close family, feared dying alone.

"Not home – last week I was going through this two day period, I was really frightened and it was scary ..." (Patient with cancer)

"I would be terrified that suddenly I was going to be left on my own for whatever reason that had happened out of the blue, that is because I live alone, if you don't live alone maybe it is different."(Patient with COPD)

"I don't want to die alone at home which could happen very easily I'd rather be here [hospice] or in hospital....it would be nice to have someone around." (Patient with cancer)

Even individuals who did not live alone also expressed a desire to access hospice care during their final days.

"At the moment home, but if things got too tough then I would be more than happy to go into the hospice. I would rather go into the hospice than into hospital." (Patient with cancer)

"I prefer the hospice because I feel safe here and confident with the medical staff and I suppose its because you need to have all sorts of medical paraphernalia." (Patient with MND)

"I'm not too sure I want to pop my clogs at my parent's house. I'd rather do it here [hospice] in the garden....and then you wouldn't be worrying about the family coping and all the rest and I know if I was in a bad way and I was here they would get looked after as well." (Patient with cancer)

It should be noted that bereaved carers whose loved ones did not have cancer advised that they were not given the choice of hospice care during their final days. The majority had died in hospital (see Section 5: Relationships, Dignity and Respect).

However, one carer recounted her story of how, with the aid of friends, her husband had been able to die at home as he wished, surrounded by his family.

"They said 'we've got to put more needles in'...he said 'no more [name]'" She[nurse] said 'if he doesn't, a week will be the longest.' So my daughter said 'well in that case, you get an ambulance and send him home.' They couldn't get an ambulance. So we know quite a few people in St Johns so St Johns Ambulance come for him that night and all of us went [to my daughter's]. And the whole family were there and he lasted a week. But there was a doctor's surgery opposite, their nurses came in – couldn't knock them – and we was all with him when he went." (Bereaved carer of patient with Parkinson's Disease)

Section summary**Preferred place of care**

- For many people, home was their preferred choice for place of care.
- Some participants were fearful of being moved to a care facility against their wishes.

Preferred place to die

- Factors that influenced choice include past experiences of places such as hospitals and hospices; perceived level of medical or personal support needed; fear of being alone or a burden to family members.
- A patient's ability to choose where to die was deemed important.
- There is a need to recognise differences and variations in where people wanted to die.
- An individual's preferred place to die appeared to be a very personal and individual choice.

5 Key Findings – Relationships, Dignity and Respect

In this section of the report we discuss patient and carer experience of dignity and respect in the care and support they received and the relationships they form with health and social care professionals.

5.1 Understanding and empathy

Relationships, dignity and respect were all central themes that emerged during the analysis of the data. Patients and carers alike expressed the value and importance of having contact and access to people who understood, empathised and appreciated the process of end of life that they were experiencing. Patients and carers who described positive experiences about the end of life care that they received invariably centred on the individuals that had been involved in that process (GPs, Nurses, Care Centre Workers, Consultants, and Hospice Staff). A number of the professionals and staff that were cited during conversations were described as “friends” able to provide both practical and emotional support to patients, carers and their families.

“Without the hospice I’d be gone, that’s physically, mentally and every other thing. This place has put me back on track and all I know is that I’ve got these people with the best backing in the world.” (Patient with cancer)

“Our relationship with our doctor was friends. He used to come in and have a laugh and a joke always because [name] knew what part of India he came from because he was out there and they used to really converse and they were friends.” (Bereaved carer of patient with MND and Stroke)

Continuity, accessibility and consistency in contact between patients, carers and key medical and social care professionals was clearly expressed by many of the sample group. For patients who were near the end of their life and their carers, the ability to have direct contact with people who would be able to offer both medical and personal advice was essential in reducing levels of anxiety and stress.

“...it was really difficult but I had a lot of support off my doctor and the community nurses and rapid response team because there were times when, and I think this is the worst bit, there were times when I didn’t know. I’d been told he was dying and had a year to live in the October, this was say February, and I didn’t know when it was going to happen and when he went into a diabetic coma or wouldn’t respond to me I thought this is it. I didn’t know and it was really frightening....one day he was very strange ... he was talking gibberish and he hadn’t done this before ... and I thought ‘that’s not right’ so we sent for the rapid response team who were on this list that the community nurses had given me and they were straight out.” (Bereaved carer of a patient with renal failure).

The need for trust and honesty was also central to these relationships; a number of people expressed their disappointment when their relationships with people or services were not maintained.

“I realised that I couldn’t trust social services to do what they said they would do. It’s OK a hospital social worker saying ‘well it’s the community health team’s responsibility to do this that and the other’, but they weren’t dealing with the day to day problems of them not turning up.” (Current carer of patient with dementia)

5.2 Dignity and Respect

The study also revealed interesting insights into the degree of respect and dignity individuals had experienced as part of their end of life care. Their personal accounts of the treatment they had received varied greatly. People expressed both negative and positive experiences. For the individuals who had particularly negative experiences, their accounts were highly emotive, passionate and in some cases disturbing.

“They would take my clothes off and throw them over me to land on the wheelchair on the other side of the bed and it was really quite a humiliating experience and I didn’t trust them to move me.” (Patient with MND)

“The last day of his life was so undignified ... when I returned my Dad was so tightly bound in the bed and he had a tracheotomy tube in and he could not move...I went back out first and I said to the nurse ‘why is my Dad like that in the bed? And she said ‘because he keeps pulling at his tube’ ... so I released him because I didn’t like the way he was bound. So I said ‘Dad I’m staying here tonight’ and I do believe he knew he was dying because he kept kissing me.” (Bereaved carer of patient with COPD)

“Our doctor came because [name] was on the settee and he said ‘look [name] if you don’t go and have these scans we cannot find out what’s wrong with you. You must go and have these scans’. And he said to me ‘if I go in I won’t come out’. Anyway he went in on January 4th, I was up there every day... and one morning I got there and he was literally sobbing his heart out. I said ‘whatever’s wrong’ He told me ‘I’ve got motor neuron and there’s no hope because there’s no cure.’ He wasn’t a bloke to cry, he was in the military police in the second world war. I mean he was 84....I was annoyed they couldn’t wait for me to get there to tell him.” (Bereaved Carer of patient with MND and Stroke)

“...on the day she [wife] died I phoned for an ambulance And when she got into the hospital ...someone came out and said “well there’s nothing more we can do”, And they moved her from A&E to the intensive care bit and put her into the [name of ward] .. and she was there for about three quarters of an hour and suddenly they decided they are going to move her....but on this last day they then moved her back into this other ward... They stuck her up in the corner in the front of a bed and there were no curtains you could pull because she wasn’t in a cubicle, she was in the front and she was stuck in the front there from roughly about 9.30 until half past four when she died, that’s where she was on display to the rest of the wardI found my wife’s treatment deplorable.” (Bereaved carer of patient with stroke)

“Can I add one thing about dignity? There can never be any dignity in a mixed ward which is what you have at the moment. Because with the best will in the world you go and visit somebody and as you are walking through like where my wife was, you had patients with mental illness as well as physical illness, and you could go in some days and there would be some poor old gentleman kicked all his covers off and he’s lying there like the day he was born Ladies used to go out to the toilet. They would put a robe round them but nobody ever bothered to tie them up and there they are walking out there for everyone to look at them. And to me, in wards like that, there is no dignity at all.” (Bereaved carer of patient with stroke)

Positive examples of carers being shown dignity and respect when their loved ones died tended to focus on the practical and emotional support they were offered as individuals.

"We were taken back in after they had taken all the machines off him and they had made the room like a little chapel with a table and flowers at the side and he was just lying there. We could have stayed as long as we wanted." (Bereaved carer of patient with heart failure)

"The hospital were brilliant, the nurses were lovely during that last night. They'd come and give me a cuddle and said 'do you want a cup of tea, do you want a walk up the ward because you'll be getting stiff? There's all sorts of noises in hospitals at night and they were lovely. It was really fantastic the care from them and the doctor at the surgery. It all helped, you know." (Bereaved carer of patient with renal failure)

"I suppose he was actually dying over a 2-3 day period and I was there all the time and they looked after me, it was the first time that I felt valued, they not only sat with me watching him die to check he was OK but also to check that I was OK and they did it in such an unobtrusive way and when he did die they checked to see that I was okay before I went home and I appreciated that a lot." (Bereaved carer of patient with dementia)"

Section Summary

Relationships, Dignity and Respect

- Understanding, empathy and appreciation of the process of end of life were seen as important qualities for end of life care staff.
- The ability to have direct contact with people who would be able to offer both medical and personal advice was seen as essential in reducing levels of anxiety and stress.
- Trust and honesty were seen as central to relationships with health and social care staff.
- Negative experiences of end of life in hospital and care home settings cited by carers were highly emotive, passionate and in some cases disturbing.
- Positive experiences focused on the practical and emotional support offered to individuals.

6 Key Findings – Information and Communication

In this section of the report we discuss patients and carers experiences of accessing information regarding their condition, treatment and support; the barriers faced by some and people's views on how information giving could be improved.

6.1 Information and Communication

As previously discussed (See Section Four: Service Provision and Integration), the transfer of information across multiple care organisations, departments and professional boundaries was perceived as inconsistent and poorly managed. Similarly, the effective knowledge management about conditions, patient requirements, and carer arrangements within organisations (between hospital departments, within GP surgeries and across social services) was also highlighted by a number of participants as poor.

Overall, information was divided into two key areas:

- Medical information on condition and prognosis; and
- Non-medical information about services, support and financial advice

One patient highlighted the fact that when first diagnosed with breast cancer she was provided with conflicting information about her condition and possible treatment options.

"I went to two different hospitals who advised different operations – one radical mastectomy and one only lumpectomy and node removal ... I was confused. Confused. I went to my GP, he couldn't help me...but at the end of the day the decision had to be mine. My overwhelming feeling at that time was there's no one I could go to. No one could help me. ..on one hand you have got one eminent surgeon telling me one thing and on the other hand I have got another eminent surgeon telling me something completely different."
(Patient with cancer)

Participants broadly felt that they were not provided with sufficient information about their condition and prognosis.

"I must say when my mum was in hospital the doctors don't give you a lot of information at all. My mum was in 10 days. I never knew what was wrong with her. I'm not one for asking questions but I used to say 'what's wrong with her?' No one never come up to me to say 'Oh your mum's got this or your mums got that. On the death certificate it's got heart failure and what's that other one they put on it - pneumonia. But no one came and told me what was really wrong with her.'" (Bereaved Carer of patient with Heart Failure)

"The only thing at the moment is, because [name] has got different illnesses and we are at different departments through the hospital, each department is very good, but we can't seem to get anyone that knows his case from beginning to end to be able to give us a prognosis. The doctor at the Macmillan's has been trying to do it but he can't get all the paperwork together because there are four different people." (Current Carer of patient with cancer)

One participant, who had cared for her friend, had found it particularly difficult to find out information about her medical condition, even though her friend's family had asked that she be given the information as she was her main carer.

“How I found out that she had a brain tumour? The carers used to have to fill in some notes that they kept in a drawer and it had something about condition or something, what was it, C2. I asked my niece because she had a friend who was a doctor... and she phoned me back and said it's not good C is for cerebral and it's tumours on the brain and I thought this is dreadful. I am the one that's looking after her and I am having to find out by devious means what's actually wrong with her.” (Bereaved carer of patient with brain tumour)

In contrast a number of participants expressed a sense that at times they had experienced information overload in relation to the condition and prognosis of the disease. This was most commonly experienced just after diagnosis or at the start of treatment. There is a possibility that this perceived information overload may be heightened by an individual's process of realisation and acceptance of illness and outcome. There was also a sense that some people looked to hospice or carer centres to support them with the absorption of information.

“You don't know what's ahead of you, you don't know, you've read all the books because you are inundated with information, absolutely inundated with information...I tried reading it all and in the end I just put it to one side, I was still in denial at that point in some respects.” (Patient with cancer)

“There's only so much we can take in, I mean my sister can probably take in a lot more because she is involved in the field, but there is only a certain amount you want to know as well. I just need to know the basics to aid me on it daily, whereas my sister would be more interested to know how one affects the other.” (Current carer of patient with heart failure)

“Living with breast cancer, sex and breast cancer, mastectomy, chemotherapy, radiotherapy, prosthesis, the operation, a lumpectomy and on and on and on. Just too much, it's too much information. Living with cancer and the last thing you want to read about when you've just been diagnosed... You've got to get you head round it first I think.” (Patient with cancer)

In one case, a patient with COPD was given a machine to help clear his airways but was not given sufficient information to use it properly. This was clearly a waste of NHS resources as they ended up throwing some of the equipment away and returning the rest to the hospital.

“I had a suction machine, but we didn't know how to use it...I had to fit it all up ...but we still didn't know how to use it. How far to put the tube in, how long to leave it in for... There were all these bits and pieces and you would look at them and think what the hell am I supposed to do with that lot? They gave us a whole box of this piping. Then they gave us those long tubes and the little tubes, this that and the other and I thought, you have given me all this stuff, how do I use it? So in the end we just threw it all away. Some of it we took back to the hospital and some of it we threw away.” (Patient with COPD)

For non-medical information about services available, support offered and financial advice, the responses from participants highlighted a general inability to access and obtain information. For many, access to financial support and advice was a priority. A number of participants suggested that a lack of support with financial problems and worries, added to the crisis and urgency of a situation.

"It makes me feel quite ignorant, because I feel that I have to really inform myself because you really need to feel like you know what your talking about, otherwise you're not taken seriously and that's a pressure really because its quite a thing to disentangle. I mean these letters, I try to understand." (Current carer of patient with heart failure)

When one participant was asked about her experience of accessing information her response was as follows:

"Abysmal, absolutely abysmal. I got nothing from social services. The approved social worker on the community mental health team, who was Dad's case worker, he was pretty good but I think he also recognised that he wasn't talking to somebody who was stupid. There is a tendency to put carers down and assume that they are all pretty well brainless, and that's not the case." (Current carer of a patient with dementia)

In addition, to the difficulties in accessing information about services, a number of people highlighted the problems they have encountered in communicating with multiple organisations. Language and literacy barriers were voiced by a number of the people that took part in the study. They described their efforts to communicate and make themselves heard as "stressful" and "like hitting your head against a brick wall".

"...last week I received a letter from the people that were looking into the investigation of the carer's allowance and they said I can't believe that you were misguided and its just like but you haven't given me any details on how you've come to this decision although I provided lots of details about my conversations and my telephone calls ...I just asked [name of Carer Centre Worker] if he could just respond and ask them what's that based on because how can they come to that decision without giving us any details. It's just nice to know that I don't have to write that letter, because there's people that are aware of the language that's required to respond to these things. Although my letter would be more of a personal one which is needed, its just taken a weight off my shoulders knowing that [name] will help me with that letter." (Current carer of patient with heart failure)

"It was like hitting your head against a brick wall, and I did actually used to come out of the conversations with them in tears and I am an articulate women who knows the system and I thought if I can't do it who can? It was almost like we had to be in a position where he was so ill, that his quality of life, that my quality of life was so bad before they would do anything to help, and what I have found subsequent to that is that there was really poor communication between the GP, social services and the community mental health team – they just didn't talk to each other." (Bereaved carer of patient with dementia)

There was a sense among some patients and carers that GP surgeries at times posed a problem for effective communication. As previously mentioned, (see *Section 5 Service Provision and Integration*), their experiences related primarily to the acknowledgement of the role of the carer in relation to the patient and their experiences of GP receptionists.

The only positive ones were my GP who supported me and the people in the end of life care centre – they were really supportive of me and everybody else wasn't and the GP receptionists were just appalling, they were really difficult.” (Bereaved carer of patient with dementia)

“Yes, the GP was one of the first people I contacted and I have still got all the documentation from it actually. I faxed him because I couldn't get through to him. They are the best gatekeepers in the world, doctor's receptionists. The only way I could get through was to fax through a consent form from my dad to say that I had found him in a real state and I wanted him to answer some questions.” (Current carer of patient with dementia)

6.2 Use of the internet

The internet had proved a useful tool for a number of patients and carers in accessing information regarding their condition and support available.

“When I was diagnosed with prostate cancer...I informed myself pretty well as quickly as I could via the internet and other means.” (Patient with cancer)

“I had to teach myself through the internet and books.” (Bereaved carer of patient with dementia)

“I have got a daughter who's got the internet, so we were looking things up on there. If I needed to I would go to the library to go on the internet.” (Patient with cancer)

In contrast there were a number of participants who did not want to access information this way, either because of the fear of fully knowing about their condition or they did not have access to such technology.

“I didn't want to go on the internet, particularly about the condition; I didn't want to scare myself and I was just confident that I was with people who would tell me what I needed to know when I need to know it and help me through.” (Patient with MND)

“Well you shouldn't have to go into the internet: a) you might not have the internet anyway and b) you may not be the type of person that is happy to sit at a computer and look at it and read all the nasty stuff that there is about pancreatic cancer or whatever it might be.” (Patient with cancer)

6.3 Ethnicity and Literacy

In a number of urban areas there was a perception among some carers that information was easier to access if English was not your first language.

“Yes, I think if you show ignorance, it seems that there is more aid somehow but I do think culturally there is more assistance if you do not have English as your first language. I think there is an automatic thing set up and all the information is provided.” (Current carer of patient with heart failure)

“If I came here and I didn't speak English I know they would have picked up easily that we wasn't getting carer's allowance, but because I am an English speaking person it was maybe assumed that I knew things.” (Current carer of patient with heart failure)

Cultural biases to how information was provided and disseminated were also perceived by some of the participants in the study.

“I think so much of the care you get very much depends on the family orientation and I would say culturally as well. I mean there are certain cultures that I think naturally find it easier to access information or it is more accessible to them, maybe because English not being their first language. Which I think is needed for that culture and the fact that there are people that are actually there to give the information.” (Current carer of patient with heart failure)

“I am not good English but I listen and like to understand. They [Carers Centre] call me, how are you, do you want help, what do you want? And they give it to me. But I said to them I am very thankful and very patient to wait for that benefit because without you I cannot receive this, so I am thankful to those people who care about me, explain and help me understand.” (Patient with heart failure and diabetes)

In contrast some participants felt that access to information was largely dependent on how forceful and articulate you were.

“Well I am a stropy cow so when I go and ask questions if I don’t get the right answers I just keep asking and asking and asking.” (Current carer of patient with dementia)

“My very first problem was that my GP told me ... that I couldn’t have a MacMillan Nurse because I didn’t have secondary cancer which is in fact wrong. So there seems to be an issue there with GP guidelines so fortunately for me I was able to articulate stuff and do my research so I contacted MacMillan through their website and sorted that out.” (Patient with breast cancer)

“At the hospital you had to ask...you didn’t always know what was happening so you had to ask.” (Bereaved carer)

“...you’re getting the information and it was easy because if you can read and write and are reasonably literate when they come and do the carers assessment you know how to cope with it.” (Current carer of patient with dementia)

Several participants felt that their literacy skills let them down regarding their ability to understand written information sent to them.

“Because I am slightly dyslexic and because you receive letters quite frequently saying your money’s going up for disability living allowance and I always call up and I always find it necessary to confirm if I understand things correctly. Maybe because of the responsibility I feel that I have and also my father questioning to see if I have understood correctly and also my feeling quite vulnerable because I am slightly dyslexic.” (current carer of patient with heart failure)

6.4 Improving access to information

A number of participants had suggestions on how to improve the ways in which information is given. This ranged from drip feeding information at appropriate times, information packs, a single point of contact for information about your condition, to a mentoring service using people with the same condition as ‘buddies’.

"It would have been really useful to have been given an information pack of where to go and what to do. It was only towards the end and I know this sounds really silly but it was all on my own shoulders and it wasn't until he had gone into [name of facility] that you saw leaflets about how to contact the Alzheimer's Society and you can talk to someone on the phone."
(Bereaved Carer of patient with dementia)

"I mean you get the initial diagnosis, your head's in a spin, you get loads of info and then there isn't really a chance to follow it up. And when the dust is settled you think 'oh my god what am I going to do about X and Y and you probably do need a contact for that?' So yes, if there was a place where they could be sure there was a contact available be it health or social care to help orient you through the morass of the system...if you had a fairy god mother like a MacMillan Nurse to come round and sit on your sofa for a couple hours, that would be wonderful." (Patient with cancer)

"Someone in the middle. Not a GP, no not a GP. I tell you what you really do need, that's someone who knows what they are talking about, someone who has been through it. Yeah! A buddy would be a good answer." (Patient with cancer)

Section Summary

Information and Communication

- Information was divided into two key areas; medical information and condition and prognosis; and non-medical information about services, support and financial advice.
- Information was sometimes conflicting or insufficiently provided.
- Some participants had experienced information overload in relation to their condition and prognosis of the disease.
- Participants highlighted a general inability to access and obtain general non-medical information.
- A lack of support with financial problems and worries was highlighted.

Use of the internet

- The internet was a useful tool for accessing information regarding their condition and support available.

Ethnicity and Literacy

- There was a perception among some carers that information was easier to access if English was not your first language.
- Some participants felt that access to information was largely dependent on how forceful and articulate you were.
- Poor literacy skills can limit understanding of written information.

Improving access to information

- A range of suggestions were provided including drip feeding information at appropriate times, information packs, a single point of contact, mentoring or 'buddy' service.

7 Key Findings – Access to Support for Carers

This section focuses on the needs of carers, their perceptions regarding their role and their specific support needs.

7.1 Carers' perceptions of their role

The perceptions of participants who supported individuals approaching end of life were mixed. A number of participants had cared for a spouse or partner for many years and did recognise themselves as the main carer within the family.

"I was a full time carer for my wife who suffered from emphysema and heart problems and I cared for her for about 13 years."

"I looked after me mother, cared for her and just over ten years ago I became a full time carer looking after her."

"I was a carer for my husband. He had Parkinson's disease and I cared for him for 16 years."

Some did not view themselves as a carer. To them it was just part of family life, something you undertook because you loved and cared for that person.

"At the time, when I was looking after my mum, I never classed myself as a carer."

"I don't think people consider themselves as carers until afterwards. Someone say to them – oh you were a carer – but when you do it to someone you love, you just do it. You're happy to help them."

"I feel more of a supportive role rather than a total caring role if I can put it that way."

"It's just the way we are as a family and it's only recently through the help of the Centre that I have recognised myself as a carer."

"I haven't registered as a carer as such because as I said it's a tradition...I think my father cares for us as much as we care for him. It's difficult to say."

Others felt that their carer role had been forced on them and one had decided to stop undertaking her caring role altogether

"Becoming a carer was sort of thrust on me."

"It's just too much and I am not prepared to lose myself again...I think now it's somebody else's turn."

7.2 Provision of carer assessments

The provision of carers' assessments was not a consistent feature among all carers that we interviewed. Over half of the current and bereaved carers were not aware or had never been offered a carers assessment.

"I never got a carers assessment. Now I don't know if that was because I didn't live with him or because I was the daughter in law? Perhaps if I had been offered a carers assessment, I wouldn't have had a breakdown." (Bereaved carer of patient with dementia)

"No, I've never felt I needed one [carers assessment], never been offered one and guess if I was offered one I'd probably refuse it. I don't feel I need it." (Current carer of patient with cancer.)

7.3 Loss of paid work

A number of carers had given up work to care for their loved ones. Some did it willingly, while others did so because the logistics of caring for someone and holding down a job became too stressful.

"I wanted to be at home with [name]....I am really pleased I finished work when I did because it meant I could take over the care of him." (Bereaved carer of patient with renal failure)

"I was given the opportunity , or I made it clear that if opportunities arose that I would be interested because we didn't know from day one we were told that [name] was terminal and therefore it was a question of how long is a piece of string. So as good as the company was, as much as I enjoyed my job, it was really a question of saying well if there's a limited amount of time, sorry I love you dearly as work colleagues but I love my wife even more and fortunately the company was very understanding and I was able to retire two years early, which was good." (Current carer of patient with cancer)

"I was living in Luton, my dad's in Nottingham ...and in the end, within a month or six weeks the pressures on me to actually give up work and move up there, it just took it's toll and in the end I just gave up work mainly because I was so tired that I just couldn't keep doing the driving." (Current carer of patient with dementia)

7.4 Carers' own health needs

Many carers were older people with health concerns of their own. Often these were neglected because of their focus on the person for whom they were caring.

"I have heart trouble myself and I was looking after her." (Bereaved carer of patient with heart failure)

"I have got a hernia in my tummy. If I start walking too far I can't breathe." (Current carer of patient with COPD)

"My husband, he is seventy-eight, he is not healthy, he has been sick as well." (Patient with heart failure)

"I must admit because one of the times he was taken ill last year in May. I had got this really dry cough and he was taken ill – me I don't care about too much. My main concern is where [name] is concerned because I know his illnesses are more important. We got to the hospital and the ambulance men said that cough don't sound too good, you had better book yourself in. Anyway it turned out that I had got pneumonia. Sent [name] home and kept me in. I was absolutely at my wits end. I was going berserk. I can't be in hospital I have got to look after my husband. They said no, sorry you're in. So I was in for three days ...but all the time I was in I was petrified whether he was alright or not." (Current Carer of patient with COPD)

7.5 Carers' perceptions of their status within society

A number of carers described themselves as feeling *"invisible"*, *"disempowered"* and *"without a voice"*. It was interesting to note that these perceptions were mainly voiced by carers of people with dementia.

"You feel that you are worth nothing." (Bereaved carer of a person with dementia)

"It makes you feel worthless and I think sometimes the only way I could fight that was to actually challenge people and to just let them know that they are not talking to an idiot." (Current carer of a person with dementia)

"It's almost like you're the dogs body that's going to do all the everyday mucky things, all the graft, but they will say that they have put a care package in place, but you are part of that care package and they are taking credit for it and the government takes the credit for it." (Current carer of a person with dementia)

Section Summary

Carers' perceptions of their role

- The perceptions of participants who supported individuals approaching end of life were mixed.
- A number of participants did not view themselves as carers. Care was just part of family life, something you undertook because you loved and cared for that person.

Provision of carer assessments

- The provision of carers' assessments was not a consistent feature among all carers.
- Over half of the current and bereaved carers were not aware or had never been offered a carers assessment.

Loss of paid work

- A number of carers had given up work to care for their loved ones. Some did it willingly, while others did so because the logistics of caring for someone and holding down a job became too stressful.

Carers' own health needs

- Many carers were older people with health concerns of their own.
- Carers often neglected their own health needs because of their focus on the person for whom they were caring.

Carers' perceptions of their status within society

- A number of carers described themselves as feeling *"invisible"*, *"disempowered"* and *"without a voice"*.
- These perceptions were mainly voiced by carers of people with dementia.

8 Key Findings – Other support needs

This section looks at other support needs of both carers and patients experiencing end of life care services including financial help and assistance, family support, emotional support and bereavement support.

8.1 Financial help and assistance

Many participants were struggling financially. Some had spent all their savings installing much needed equipment within their homes, whilst for others becoming ill had meant giving up work and the loss of financial independence.

*“I’ve gone through £12,000 in savings in the last two years...now I’m on pension credits.”
(Bereaved carer of patient with heart failure)*

“I was self employed and being self employed I’d paid all my stamp, all my taxes and everything was up to date...Everything was alright but then I couldn’t work...I had to fill this form in and the man said it will take you about half an hour to fill this form in over the phone. Two and half hours later I was still on it and at the time I couldn’t even breathe so after ten minutes I was shattered.” (Patient with cancer)

“I had no money for eight months; I had to borrow money off [sister’s name]. She used to go shopping to feed us because we couldn’t feed ourselves. We were told to go for a crisis loan...so I go...and they say you are not eligible for it and I ask why and he said because you’re not.” (Patient with cancer)

Only one person advised that they did not need financial help. This was because they had worked as a payroll officer and knew where to go for help. The importance of gaining assistance in claiming financial benefits were emphasised by the majority of participants. Many people had been unaware of certain benefits they could claim for and others had filled in forms incorrectly and had been refused help. Carer Centre and Hospice support workers were highly praised by both carers and patients in providing support with completing complex application forms in order to gain much needed financial support.

“My parents don’t read or write English, so I have had to deal a lot with the correspondence and I think the thing that I found difficult was just understanding.” (Current carer of patient with heart failure)

“[Name] worked at the hospice and she sorted out all the things that I could claim for, she did that. She used to come and sit down and have a little natter for an hour and that was her job. Then she found out that I hadn’t filled in these forms and whatever, so she did it for me, where I’d be left hanging on, she could get directly through.” (Patient with cancer)

“The [name of Carers Centre] sorted out my pension for me and everything...and where [name]’s disability allowance was concerned, he has sorted that out for us.” (Current carer of patient with COPD)

“I think you do need a good Macmillan Nurse because it was only through [name] that we found out about disability living allowance, about things like the blue badge, carers allowance, all these sort of things. If it hadn’t been for [name] we would never have known about those, so they’re no things that seem to be widely published shall we say...I certain would say that the hospital didn’t point us in any of those directions and there is perhaps a gap.” (Patient with cancer)

One participant explained that by the time her friend's financial situation was assessed, her health had deteriorated to a point that she found the whole process extremely stressful.

"They came to assess [name]'s financial situation with a regard to paying for the services, now that was a bit late.. because she was in no state and the man was here for nearly an hour and a half and in the end she said 'send him away, send him away.'" (Bereaved carer of patient with a brain tumour)

Other carers stated that if you were claiming disability benefit yourself, or you were retired, you were unable to claim.

"..because I have a disability myself, I couldn't claim for caring for my Dad. My argument is that if we weren't there to care for our loved ones, the government would have to fork out the money to care for these people and it seems the more you will care for someone the more the government will stand back and let you get on with it and make you fight for what you think is yours all the time." (Bereaved Carer of patient with heart failure)

"The thing is when you are a carer, when you turn 65 you can't claim it because it's two benefits, because they consider your state pension a benefit. The fact that you've paid for it and worked 40 years for it, doesn't count. So you are now an unpaid carer." (Bereaved carer of patient with Stroke)

8.2 Direct Payments

Two participants interviewed had accessed direct payments and were pleased with the standard of the care they were receiving. They both spoke about the fact that they had been able to personally employ care workers themselves and that this enabled services to be designed and organised around their specific needs.

"Basically I knew it [direct payments] existed because when I was a journalist I wrote about it. When I was first ill I had an hour a week – home from hospital – they would come at 11 o'clock and put you to bed at 12 o'clock so you were up for about an hour a day. So then I spoke to social services and I found out about direct payments, got that, and I got somebody and then it was fine." (Patient with cancer)

"We are on direct payments so my husband can go for his respite every six weeks. When he goes off and does his own thing...I have a carer that lives just around the corner from us and I employ her and she comes in and does what I want her to do. I find it good for me. ...I could have had agency staff but I didn't want that because it is different people all the time. I just wanted one person that knows me and has one set of keys." (Patient with MS)

In contrast, a patient who relied on agency night staff, provided for her, found the lack of flexibility they offered resulted in a poorer quality of care provision.

“I was having the night nurses calling in but it was difficult to contact them if you didn’t need them because you had to go through some agency and you had to give them the address and telephone number of your GP and really all you wanted to do was say ‘I’m not going to be in tonight so please don’t get the emergency services to knock the door down. There didn’t seem to be a way of actually contacting them directly. Its like today, if I want a nurse when I get home, say I want a comfort break, I would have had to book before nine o’clock this morning because they have a rota. They don’t take bookings after four o’clock and the night nurses don’t start until six o’clock.” (patient with MND).

The consensus of opinion was that information about financial assistance should be easily available and simple and quick to access. As one patient stressed:

“All of these services are absolutely basic and therefore it should be for absolutely everybody who needs it, not just people finding things out for themselves but it actually needs to be served on a plate a little bit more.” (Patient with cancer)

8.3 Family Support

Many participants expressed the importance of friends and family in helping them cope with either their illness or their caring role.

“Well I had two children who were the main support and I have two very special friends. Like one time we had to go in the middle of the night and I couldn’t drive and my friend got out of bed at three o’clock in the morning to take me to the hospital.” (Bereaved carer of person with renal failure)

“I am one of the lucky people. My daughter will take me anywhere I want to go. ... I don’t know what I would do if/when they get married they decided to move back up to Sheffield, I will be absolutely lost.” (Current carer of person with COPD)

“My children are good to me, they help me a lot. My daughter comes here and cleans the house.” (Patient with heart failure)

“My husband does everything.” (Patient with MS)

In contrast, those that did not have such support often felt alone and isolated. For patients, this could lead to a fear of becoming extremely unwell or dying alone whilst carers expressed feelings of loneliness and sadness.

“The family didn’t want to know, because they couldn’t cope with his condition. My husband couldn’t because he was away on business for the whole year...and at the time I felt really bad.” (Bereaved carer of patient with dementia)

“I don’t want to die alone at home which could happen very easily. I’d rather be here [hospice] or in hospital...it would be nice to have someone around.” (Patient with cancer)

“...when my husband died he [son] said he had to get back to his wife...I just pretended that it was alright.” (Bereaved Carer of patient with heart failure)

8.4 Emotional Support

The importance of being able to access emotional support was emphasised by many participants. Many patients spoke about their experience of depression and although family support was seen as very important, sometimes people preferred to talk to a third party outside of the family about their feelings and concerns for the future.

*"...we did get support, from our family, the love and care for each other in this house."
(Bereaved carer of patient with dementia)*

"I got to the stage where there was no one I could talk to that wasn't personally involved with me. I felt as if I was protecting them. Does that make sense?" (Patient with cancer)

"I was terribly depressed....then I met [name of MacMillan Nurse] and she lifted me up and she's just the best. She's at the end of the phone whenever I need her and she will be here within an hour if I needed her to be. But even speaking to her on the phone she will lift me up." (Patient with cancer)

"I would go to counselling...because I was getting to be a bit of a pig. I could see myself shouting and getting down and I started taking it out on people." (Patient with cancer)

Those that did not have access to hospice care often relied on their GP or primary care team for support.

"...if I am very depressed and I am not feeling well, if I saw my GP and he talked to me, I feel good, I feel better." (Patient with heart failure)

"...they [community nurses] were the best friends we ever had....if I needed them I just rang them up." (Bereaved carer of patient with renal failure)

One participant who had been unable to gain emotional support from either family or any health or social care staff explained how the stress of looking after her relative had left her exhausted and eventually ill herself.

*"...you get to a stage that you are so emotionally tired, everything is all going at you, like a tidal wave coming at you and you just are not really sleeping, as you are worrying about him...I became unwell because I had been worrying and you just get really really tired."
(Bereaved carer of patient with dementia)*

8.5 Bereavement Support

Bereaved carers described how empty their lives seemed after their caring role had ended particularly if they had been caring for many years.

"I didn't want to do anything. I just felt my life was finished." (Bereaved carer of patient with heart failure)

"...suddenly you've got this great big void because every minute has been so concentrated and then suddenly there is a big emptiness, you almost feel you want to find somebody else who needs looking after." (Bereaved carer of patient with renal failure)

It was interesting to note that no carer we spoke with had been offered help in organising the funeral or helping to get their finances in order after their loved one had died. Two people however had been able to access counselling through their GP or social worker and others found their local Carers Centre very supportive.

"I did go for counselling for 12 weeks....I was walking around in a daze, I didn't know if I was coming or going. The woman was very good, she said if you have any more problems you can always come back." (Bereaved carer of patient with heart failure)

"My son found out about here[Carers Centre] and he said 'Mum you've got to make your own life....he said for the last six months you've had no life, you've got to go out'. I didn't want to do anything. I just felt my life was finished so I've come and seen [names of Carer Centre Staff] and they were absolutely brilliant." (Bereaved carer of patient with MND and Stroke)

Section summary

Financial help and assistance

- Many participants reported that they were struggling financially.
- Many people had been unaware of certain benefits they could claim.
- Accessing financial help was reported as being difficult and stressful.

Direct Payments

- Only a small minority of people had taken advantage of direct payments.
- They reported an improved quality of care because they could personally organise their own care to meet their specific needs. This had resulted in gains in independence and flexibility of care benefiting the whole family.

Family Support

- Many participants expressed the importance of friends and family in helping them cope with either their illness or their caring role.
- Others who did not have such support reported often feeling alone and isolated.

Emotional Support

- The importance of being able to access emotional support was emphasised by many participants.
- Some people preferred to talk to a third party outside of the family about their feelings and concerns for the future.

Bereavement Support

- After their caring role had ended, bereaved carers described how empty their lives seemed, particularly if they had been caring for many years.
- None of the carers interviewed had been offered help in the organisation of funerals or helping to get their finances in order after their loved one died.
- A minority of carers had been offered counselling. They reported that this support had been helpful.

9 Key Findings – Main issues and future changes/improvements

This section of the report details the issues that affect patients and carers who are accessing end of life care services and their views in relation to desired future changes to service provision

9.1 Issues that affect patients and carers who are accessing end of life care services

The main issues that were highlighted by participants for the study included:

Equity and consistency of access to services	Lack of dignity and respect of patients and carers	End of life care within hospital settings	Training
Flexibility of service delivery	Poor integration of lack of cohesion between services	Wheelchair provision	Withdrawal of life prolonging drugs
Preferred place of care	Information and communication	Financial help and assistance	Emotional and bereavement support

9.1.1 Equity and consistency of access to services

Many participants felt that the distribution of end of life care services and support was not equitable or consistent across all disease groups. In particular, carers of patients who had extreme frailty or were experiencing dementia often felt that their needs were treated differently from those with cancer.

“He received a different level of care in my opinion. It actually made me feel that he was a second class citizen. It actually made me feel that he wasn’t as important as someone with cancer.” (Bereaved Carer of patient with dementia)

In some cases, carers described their frustration at trying to access social care and often felt “disempowered” and “without a voice”.

In addition, for some individuals, respite care was difficult to access. Unlike patients with cancer who often obtained respite within a hospice setting, patients with frailty or dementia could only access respite within care homes and in a number of cases, carers reported inadequate service provision.

“...I went down there and it was half past twelve and he was in bed and he had his breakfast by the side of him. He had about three days growth [of beard], the room smelt terrible and these was all discarded clothes and everything.” (Bereaved carer of patient with Parkinson’s Disease)

9.1.2 Lack of dignity and respect for patients and carers

Participants reported a lack of dignity and respect in a number of care settings. In particular, very negative experiences were expressed regarding hospital care (see below 9.1.3).

One area for improvement cited by a number of participants was the attitude of GP receptionists who were viewed as rude and a barrier between patients, carers and their GP.

"...getting through a barrage of battleaxes on reception who say things like 'no you can't have a flu jab' or 'no you can't see the GP, he's busy for the next six weeks or whatever and you have to break confidentially by constantly telling people who you don't know your medical history in order to get anything." (Patient with cancer)

A number of carers mentioned the need to stop the use of mixed wards emphasising that such units resulted in loss of patient dignity.

"There can never be any dignity in a mixed ward. ... you could go in some days and there would be some poor old gentleman kicked all his covers off and he's lying there like the day he was born. Ladies used to go out to the toilet. They would put a robe round them and nobody every bothered to tie them up and there they are walking out there for everyone to look at them. And to me, in wards like that, there is no dignity at all" (Bereaved carer of patient with stroke)

Lack of dignity and respect during death within acute settings was also highlighted during the study.

"...on the day she [wife] died I phoned for an ambulance And when she got into the hospital ...someone came out and said "well there's nothing more we can do, And they moved her from A&E to the intensive care bit and put her into the [name of ward] .. and she was there for about three quarters of an hour and suddenly they decided they are going to move her....but on this last day they then moved her back into this other ward... They stuck her up in the corner in the front of a bed and there were no curtains you could pull because she wasn't in a cubicle, she was in the front and she was stuck in the front there from roughly about 9.30 until half past four when she died, that's where she was on display to the rest of the wardI found my wife's treatment deplorable." (Bereaved carer of patient with stroke)

9.1.3 End of life care within hospital settings

Although a number of participants praised the care they had received within an acute setting, this positive experience tended to focus on the people with whom they had the most contact, such as their primary consultant.

In contrast, other individuals had expressed very negative feelings towards their treatment and interaction with acute services particularly around consistency of the care experienced, equipment and food.

A reason suggested for this lack of consistency was the prevalence of agency rather than permanent staff on wards. It was suggested by some participants that difficulties arose due to poor language skills and a lack of commitment to the people they were looking after.

“If the hospital had been like my wife’s GP it would have been great but you’ve got too many agency staff that when you complain they turn round and say to me “I’m not particularly bothered I can leave here and get another job tomorrow.” (Bereaved carer of patient with emphysema and heart failure)

“...there is a need to have decent, fully trained staff that are training in this country to this country’s standards not agency staff that can’t even speak English.” (Bereaved carer of patient with COPD)

9.1.4 Training issues

The need for better end of life care training was emphasised. This issue was highlighted by a number of carers particularly around the quality, training and level of experience of the social care workers they encountered. Home care workers were often seen as inadequately trained and unable to understand or meet patient needs.

“I was absolutely appalled by the fact they are just not trained. I remember coming home one day and there was this, well I would call her a girl, she was about 16 years old – she had no training in dementia and I arrived ...and he said ‘I’m so cold’ and I took his coat off and all he was wearing was a pair of socks and underpants and she was supposed to be caring for him...she was just completely out of her depth. ...and if that the quality of home help coming in then...I don’t know how widespread it is, I can only talk from my experience.” (Bereaved carer of patient with dementia)

9.1.5 Flexibility of service delivery

Lack of flexibility of services was also highlighted. Again this tended to be around home care. Patients explained that often their daily activities tied around agency staff rotas and the working day.

“I was having the night nurses calling in but it was difficult to contact them if you didn’t need them because you had to go through some agency and you had to give them the address and telephone number of your GP and really all you wanted to do was say ‘I’m not going to be in tonight so please don’t get the emergency services to knock the door down. There didn’t seem to be a way of actually contacting them directly. It’s like today, if I want a nurse when I get home, say I want a comfort break, I would have had to book before nine o’clock this morning because they have a rota. They don’t take bookings after four o’clock and the night nurses don’t start until six o’clock.” (patient with MND).

Only two participants were currently accessing direct payments but were very complementary about this type of provision and had seen the quality of their lives drastically improved as they were able to plan their care around their specific needs.

“We are on direct payments so my husband can go for his respite every six weeks. When he goes off and does his own thing...I have a carer that lives just around the corner from us and I employ her and she comes in and does what I want her to do. I find it good for me. ...I could have had agency staff but I didn’t want that because it is different people all the time. I just wanted one person that knows me and has one set of keys.” (Patient with MS)

However during conversation, it was clear that many participants were unaware of this benefit and, once made aware, appeared keen to explore this avenue of financial assistance.

9.1.6 Poor integration and lack of cohesion between services

A large number of participants felt that there was little integration across services, that they were disjointed and lacked a “common sense” approach to patient care.

“...I don't think the left hand has time to find out what the right hand is doing; there just isn't one person on top of the whole thing.” (Patient with cancer)

“I said to Dr X, ‘those nurses you've got coming round’ and he said ‘I don't know anything about that’, he said ‘we don't talk about that’. They are two separate departments.” (Current carer of patient with COPD)

“It's time to go home [from hospital] which is on Christmas Eve. They have done this package for me. People are going to come out to visit me, I am going to get meals on wheels and get this, that and the other. Nothing happened until February.... I am at the pity of all my neighbours, because they are bringing me food in, there's nothing in the fridge and I can't go shopping because I am so breathless.” (Patient with cancer)

An idea for improving co-ordination of services cited by a number of patients was that each patient should have a key contact who would gather all information about their care and support needs. Patients explained they would find it useful to have one person who they knew they could ring up for help and advice and who would be able to help them access support quickly.

9.1.7 Wheelchair provision

A number of both patients and carers reported difficulties in obtaining appropriate wheelchair provision. Many carers were older people with health needs of their own and found it difficult or impossible to push a wheelchair. Many expressed their wish for access to an electric wheelchair explaining it would give them more freedom and improve their quality of life.

“the thing my pushchair, my wheelchair, if nobody push me how can I go out? ...so I said to [name] because they ask me and I said I want a little bit of electric something like that. I could use the electric one quite easily. That's what I want. I could go in the garden and look around there. My husband cannot manage to push me.” (Patient with heart failure)

9.1.8 Withdrawal of life prolonging drugs

Only two patients reported that their life prolonging drug therapy had been withdrawn or refused which had caused them anger and frustration. However, the decision was made even harder by the impersonal nature of the decision to withdraw such medication by the PCT.

“the application was dealt by what they call a virtual panel. Over four days, two of which were a weekend and I can't imagine that those four people spoke to each other over a Saturday and Sunday....I've discovered they didn't even speak to my oncologist; they didn't speak to me, there was not an oncologist on the panel, there was no independent voice on that panel to speak to me and I feel they just dealt with my case by a cursory glance, no she's not having that drug, end of story. At a time when I should be enjoying every last minute, I am having to fight for a drug ...” (Patient with cancer)

It is suggested that PCTs review their procedures in these cases and ensure that patients feel included in the process and that any decision to withdraw medication is fully explained in person rather than via letter or email.

9.1.9 Preferred place of care

Patients preferred place of care and their preferred place to die was influenced by a number of factors. This included past experience of places such as hospitals or hospices, the level of medical or personal support available, their personal fear of being alone or a perceived burden it would place on the family.

*"I'm not too sure I want to pop my clogs at my parent's house. I'd rather do it here [hospice] in the garden....and then you wouldn't be worrying about the family coping and all the rest and I know if I was in a bad way and I was here they would get looked after as well."
(Patient with cancer)*

A number of carers explained that individuals who had died of conditions other than cancer usually did not have the option of choosing hospice care at the end of their lives. Watching their loved one die in an acute setting was not seen as appropriate and often had been a harrowing experience for carers. In some cases difficulties had been encountered when trying to move the person who is dying back home and improvements should be made to ensure such support is available.

However, participants emphasised that it is important for health and social care professionals – both policy makers and care staff – not to assume that everyone wishes to die at home. Such a decision is a very personal and individualised choice and participants felt that all patients should be fully supported in their particular choice.

9.1.10 Information and communication

The transfer of information across multiple care organisations, departments and professional boundaries was perceived as inconsistent and poorly managed. Similarly, the effective knowledge management about conditions, patient and carer requirements and arrangements (between hospital department, within GP surgeries and across social services) was also highlighted by a number of participants as poor.

People reported having either too little information or conversely too much leading to information overload. There was also a perception by some that information was easier to access if English was not your first language because allowances were made for such groups.

Ideas for improvements ranged from drip feeding information at appropriate times, information packs, a single point of contact for information, to a mentoring service using people with the same condition – “buddies”.

9.1.11 Financial help and assistance

Many participants for the study struggled financially. There was a general lack of knowledge around what financial benefits were available and many expressed the difficulties they had experienced in trying to access financial support, particularly when completing forms.

"I had no money for eight months; I had to borrow money off [sister's name]. She used to go shopping to feed us because we couldn't feed ourselves. We were told to go for a crisis loan...so I go...and they say you are not eligible for it and I ask why and he said because you're not." (Patient with cancer)

Voluntary organisations such as hospices and carers centres were very much appreciated for offering much needed support in helping people to claim the financial benefits to which they were entitled.

9.1.12 Emotional and Bereavement support

The importance of accessing emotional support was emphasised by both carers and patients. Depression was common and although family support was seen as very important, sometimes people preferred to talk to a third party outside of the family about their feelings and concerns for the future.

A number of bereaved carers had been offered counselling and had found this useful. However, it was noted that no bereaved carer interviewed in the study had been given information regarding organisation of funerals, death certificates or organisation of their financial affairs.

"I did go for counselling for 12 weeks....I was walking around in a daze, I didn't know if I was coming or going. The woman was very good, she said if you have any more problems you can always come back." (Bereaved carer of patient with heart failure)

Section Summary

Main findings and future changes/improvements

A range of improvements were identified by both patients and carers regarding improving end of life care services. These included:

- Improvements in equity and consistency of access to services across all disease groups;
- Access to high quality respite care should be available to all individuals receiving end of life care services;
- Training, particularly around dignity and respect at end of life care should be made compulsory for all health and social care staff, including GP receptionists;
- Improved access to carer assessments;
- The removal of all mixed sex wards should happen at the earliest opportunity;
- There should be an increase in permanent nursing staff on hospital wards in order to improve continuity of care;
- More information should be made available regarding accessing direct payments;
- There should be one key contact for patients and carers to access information and support regarding their specific needs;
- Improvements in the availability of electric wheelchair provision;
- Improvements in PCT procedures regarding reviewing access to life-prolonging drug therapies;
- Improved information provision including information packs containing health and social care information, a single point of contact and mentoring service for patients and carers; and
- Easy access to counselling for both patients and carers.

10 Recommendations for discussion and further consideration

Based on our research findings, consideration should be given to the recommendations listed below. It should be noted that these are based on a small number of views and should therefore also be considered in light of the findings from the additional aspects of work being undertaken by the NAO into end of life care services.

Although the positive and negative information gleaned from the participants for this study is both powerful and, in some cases, moving and disturbing, they are examples of individual experiences of patients and carers who have accessed end of life care services. Without wider research and further discussion these findings and resultant recommendations should not be interpreted as being necessarily representative of all patients and carers experiences in relation to end of life care services in England.

Recommendations

1. Consideration should be given to improving local co-ordination and integration between health and social care providers of end of life care services.
2. Local Primary Care Teams should maintain a database of carers and ensure that individual carer support needs are assessed at regular intervals, including access to respite care, counselling and home care and support services.
3. High quality respite care should be made available to all individuals receiving end of life care services. Consider unannounced inspection visits to all care home facilities to ensure high standard of care.
4. Easy access to counselling should be available for both patients and carers, including bereavement counselling.
5. Training, particularly around issues of dignity and respect should be made compulsory for all health and social care staff, including GP receptionists.
6. Clear information in relation to the following areas should be made available through all health and social care staff: If possible, patients and carers should be given the name of a key contact who fully understands their specific needs. Information offered should include:
 - Practical advice regarding managing finances and applying for welfare entitlement;
 - Information on condition and progress and prognosis;
 - Information about community equipment, including wheelchair provision;
 - Information about local services, including an easy to access contact list for both medical and social care support services; and
 - Information regarding preparation of wills
7. Permanent nursing staff on hospital wards should be increased in order to improve continuity of care.
8. PCTs should review their procedures for patient appeals regarding access to life-prolonging drug therapies.

Appendix A

**Summary Table of
Interviews and Focus
Groups**

Summary Table of Interviews and Focus Groups

Participant Group	Number of Participants	Male / Female	Age Range	Focus Group / Interview	Location	Participant information	Rural / Urban
Patients	3	2 Males 1 Female	Retired	Focus Group	Trinity Hospice, South West London	<ul style="list-style-type: none"> Cancer Patient COPD Cancer Patient 	Urban
Patients	3	2 Females 1 Male	2 x Working Age 1 x Retired	Focus Group	Trinity Hospice, South West London	<ul style="list-style-type: none"> Breast Cancer MND Liver Cancer 	Urban
Patient	1	Interview	Retired	Interview	Sue Ryder Home, Peterborough	<ul style="list-style-type: none"> MS 	Urban
Patient	1	Interview	Retired	Interview	Sue Ryder Home, Peterborough	<ul style="list-style-type: none"> MS 	Urban
Patient	1	Female	Retired	Interview	Kent	<ul style="list-style-type: none"> Cancer & Lupus 	
Patient	1	Female	Retired	Interview	Tower Hamlets	<ul style="list-style-type: none"> Patient with COPD and associated co-morbidities 	Urban
Patient	1	Female	Working Age	Interview	Kent	<ul style="list-style-type: none"> Cancer Patient 	Rural
Patient and Current Carer	2	Patient – Male Carer – Female	Retired	Interview	Tower Hamlets	<ul style="list-style-type: none"> A husband and wife focus group, the husband has a co-morbidity of conditions including heart failure, COPD, and diabetes 	Urban
Bereaved Carers	7	3 Males 4 Females	Working Age & Retired	Focus Group	Tower Hamlets	<ul style="list-style-type: none"> Heart Failure Stroke Parkinson's Disease MND 	Urban
Bereaved Carers	2	2 x Female	Retired	Focus Group	Sunderland	<ul style="list-style-type: none"> Bereaved carer, cared for husband with kidney failure Bereaved carer, cared for husband with a co-morbidity of conditions 	Urban
Bereaved Carer	1	Female	Working Age	Interview	North Yorkshire	<ul style="list-style-type: none"> Bereaved carer, cared for father-in-law with dementia 	Rural
Bereaved Carer	1	Female	Retired	Interview	North Yorkshire	<ul style="list-style-type: none"> Bereaved carer, cared for friend with cancer 	Rural
Bereaved Carer	1	Male	Working Age	Interview	South London	<ul style="list-style-type: none"> Dementia 	Urban
Current Carer	1	Male	Retired	Interview	Kent	<ul style="list-style-type: none"> Current carer for a cancer patient 	Rural
Current Carer	1	Female	Working Age	Interview	Tower Hamlets	<ul style="list-style-type: none"> Current carer of patient with stage 3 heart failure 	Urban
Current Carer	1	Female	Working Age	Interview	Tower Hamlets	<ul style="list-style-type: none"> Current carer of patient with dementia 	Urban