

Person-Centred Support: choices for end of life care



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We would like to thank all the service users, practitioners, managers, trainers, colleagues and friends who took part in this work and supported us to do it. Without you this Project would not have happened and this guide could not have been written. We hope this guide is useful in making person-centred support happen for all service users.

The Standards We Expect Consortium



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The Standards We Expect Project

Published in 2011 by
Shaping Our Lives
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London WC1N 3XX
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In association with
The Joseph Rowntree Foundation
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York YO30 6WP
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ISBN 1 874436 71 1

Front cover illustration © Kevin Chettle
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Designed by Julie Rimmer 020 7228 7912

Printed by Pureprint Group Ltd

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Foreword

I am delighted to provide the foreword to this excellent report. The study highlights many of the issues we have been working to overcome at the National Council for Palliative Care (NCPC). Our role in leading the Dying Matters Coalition is to reduce the certain taboo which exists around discussing dying, death and bereavement. It is this taboo which leads, in many cases, to our not discussing our wishes and therefore our wishes not being met. We need to create a culture where staff, residents and families feel able to openly discuss their wishes and their fears, make informed choices and get the end of life care they wish for. It is simply not good enough in 2011, with the excellent services which exist, that so many people are not in the place they choose, with the people they choose, accessing the care they choose at the end of their lives. A good life deserves a good end for the resident themselves, their loved ones and the staff who care for them. I hope that commissioners and providers of services take note of this report and tackle these issues. We all deserve to die well and together we can achieve this.

Eve Richardson Chief Executive of NCPC and the Dying Matters Coalition

Executive Summary

The Standards We Expect Project was a national research and development project funded by the Joseph Rowntree Foundation examining the barriers to person centred support and how they might be overcome. The project supported the development of person centred approaches by working in partnership with individual social care services across the United Kingdom. It aimed to work with a diverse range of people using and providing a wide number of different services.

As part of this programme a small qualitative research project was undertaken in Camchester. The work was led by a steering group of local experts ranging from primary and secondary care professionals to relatives and carers of people living in nursing and residential homes. Its subject, choices in end of life care, grew from local concerns that nursing and residential homes are very often admitted to hospital during the final phase of life. These admissions may not be what a resident might choose and could be against previously expressed wishes.

It aimed to collect the views of:

- People living in nursing and residential homes
- Relatives and carers of people living in homes (or those whose loved ones had recently died)
- Practitioners and managers working in homes

The project wanted to find out what participants thought were the barriers to support being person centred at the end of life and how these barriers might be overcome.

METHODOLOGY

The study was based on five nursing and residential homes and comprised of semi structured interviews with 33 people and a focus group of a further seven carers and relatives. It was conducted over the period of a month in August and September 2007. Given the sensitive nature of the subject all participants went through a three stage consent process and were given information about (and contact details for) relevant support and counselling services.

CONCLUSIONS

The main conclusions of the study were:

- Most residents reported that they were content with the care they receive at their nursing and residential homes.
- Many residents said they had not thought about or discussed end of life decisions.
- Only a minority of residents said they had spoken about end of life care with nursing or residential home staff.
- Many relatives are making important end of life decisions on behalf of their loved one. Some residents said they were happy for their relatives to make these decisions on their behalf.
- No residents we spoke to had advanced care directives.
- Several residents had thought about and made decisions about their funeral. This was one area about the end of their lives that the majority of residents had made decisions about.
- There was a widespread reluctance among practitioners to talk about end of life choices with residents. Many staff said that it was difficult or inappropriate to have these discussions before they built a relationship with a resident.
- Practitioners described a traditional reluctance in nursing and residential homes to tell residents about the death of their fellow residents.
- Some participants described insufficient staffing levels to provide good practice end of life care.
- End of life paperwork must be signed by all necessary parties, including GPs. Without these signatures there can be problems of people being admitted to hospital who had previously expressed a wish not to be.
- Several residents who made the choice to die at their care home rather than hospital were able to achieve this. However some traumatic incidents were described of people being admitted to hospital.
- Some practitioners said they fear being criticised for not making attempts to resuscitate residents, even if this is against the resident's stated wishes.
- A lack of organised support for staff who may be distressed at the death of residents was described in some homes.
- There were very few residents from ethnic minority groups at the nursing and residential homes in our study.

RECOMMENDATIONS

Individual choices

1. Residents of nursing and residential homes should, whenever they have capacity, make decisions for themselves. Homes should ensure that their policies and procedures fully reflect the principle and requirements of the Mental Capacity Act (2005).
2. Nursing and residential homes should build links with local advocacy organisations and support residents to access advocacy.

General

3. There should be a more general openness about the subject of death for all people. Efforts should be made to promote an earlier consideration of end of life choices amongst the general public.
4. Many service users admitted to nursing and residential homes from hospital have previously answered questions about their end of life wishes. Transferring this information to the home would be a useful interim measure.
5. Residents in nursing and residential homes benefit from time to consider their options relating to end of life decisions. Therefore it is important that those practitioners, relatives and GPs involved are able to take the necessary time to support informed and considered decision making.

Nursing and residential homes

6. There should be more openness about dying and death within care homes; this would enable residents, relatives and practitioners to talk honestly about end of life choices at an earlier point.
7. Nursing and residential homes are required to have a policy about end of life care. Residents and their relatives could play an important role in the process of developing end of life care policies.
8. Further research may be of benefit in examining cultural awareness in nursing and residential homes and to look into the apparently low number of people from black and minority ethnic groups moving to a home.

Training

9. There is evidently a need for regular staff training around choices in end of life care. We understand this training is available locally and would encourage managers and practitioners from all nursing and residential homes to attend.

10. If nursing homes are expected to take on residents with more complex palliative care needs their staff would benefit from access to the training available to PCT staff through the Regional Collaborative.
11. Commissioners could consider minimum standards for elements of end of life care choices as part of the commissioning process. For example specifying training requirements relating to choices in end of life care in Service Level Agreements.

Relatives and carers

12. Support groups for relatives and carers of residents have been established in several homes in Camchester. The groups should be supported by homes but run and governed by residents/relatives.
13. A booklet for relatives and carers providing information about options towards the end of life and what to do when their loved one dies would clearly be useful. Building on the existing work of a number of homes this resource should be developed so that every home can hand it out as and when needed.

Resuscitation

14. It is essential that the necessary, signed paperwork is available for people who have specified a wish not to be resuscitated or for whom resuscitation is not clinically indicated. Deficiencies in this paperwork can lead to distressing and traumatic incidents at the end of life.
15. (See Appendix 2) The potential for an extended role of nurses in making judgements about treatment at the end of life could help ensure service users' decisions are respected.

GPs

16. GPs should discuss choices in end of life care with their patients who live in nursing and residential homes.
17. The study found that the quality of relationships between nursing and residential homes and GPs vary. Some problems arise from homes having to link with a number of different GP practices. If residents from each home were given the option of joining the list of a single GP practice (with established links to that home) improvements could be made in continuity of care.
18. Efforts should be made to improve the quality of relationships between nursing homes/residential homes and 'out of hours' GP services.

Introduction

The aim of the Standards We Expect Project was to attempt to encourage and guide the development of systems and processes to support social care service users to determine how their rights/needs are met, through a process of involvement and negotiation among key stakeholders, sharing and exchanging with a wider network.

As part of the wider Standards We Expect Project a small qualitative research project was undertaken in Camchester.

The aims of this research were to:

- Collect the views of residents, their carers or relatives of older people living in independent care homes and staff in care homes.
- Explore with them the barriers to person centred support at the end of life.
- Consider how to enable staff to facilitate choice for service users and their carers – i.e. empower and introduce shifts in the prevailing culture to enable older people to exercise choice.
- Consider the configuration of services needed to provide the choices expressed by service users and carers.
- Develop a plan of action to act on findings of the research.

This report was written for one of the Standard We Expect Project's service partners. The identity of the service is concealed in order to protect the anonymity of those involved. Therefore the fictional name of Camchester has been used, replacing the real name of the City involved.

The Joseph Rowntree Foundation funded the Standards We Expect Project which is supporting the research in Camchester into end of life care. This is a two year project which seeks to support the development of improved person centred services. In Camchester this is focused on examining end of life care and choice for older residents of nursing and residential homes.

The reason this area of work was identified chosen was initially based on anecdotal evidence that patients/residents of care homes in Camchester are very often admitted to hospital during the final phase of life. This could be days or even hours before death, with no apparent consideration of patient choice. Also perceptions were expressed across a range of providers that standards and practice at end of life differ between care home facilities.

National research into this further supports the concept that older people wish to engage in decision making about end of life issues (Seymour et al 2005)¹, including level of active intervention and place of death, but are given little opportunity to do so. Therefore involving and engaging carers and users of services, empowering them to make active and informed choices when planning and developing structures to support individual decision making processes is key to achieving the desired outcome.

The recent White Paper, Our Health Our Care Our Say² requires “More rigorous fulfilment of existing duties to involve and consult the public in how services are provided” and specific action to improve end of life care including establishing “end of life networks”. In looking at admissions from care homes to the Acute Hospital Trust over a three month period in mid 2006, 500 patients were admitted, of whom 50 (10%) died. The remainder either returned to their place of origin or were re-assessed and moved to a higher level care facility.

Locally, there are other initiatives currently being developed which support the idea of reducing the number of patients inappropriately admitted to hospital and of enabling people to die in a place of their choosing. Clearly these goals are complementary with the aims of this project and include admissions avoidance schemes and the POPPS³ project, which aims to improve the well being of older people, involving them in decision making and focusing care and service delivery where users really want them to be.

The project is guided in Camchester by a multi-professional project group with members from both primary and secondary care and includes people who have a declared interest in end of life issues and choice, but who are also able to support the research process and to influence change in practice where necessary. The majority of the group are clinicians working in this field with carers and older people also represented.

More rigorous fulfilment of existing duties to involve and consult the public in how services are provided and specific action to improve end of life care including establishing ‘end of life networks’. **Department of Health**

Methodology

This is a qualitative study that values people’s first hand experience as a basis for knowledge. This qualitative study has fallen into a number of stages:

- Find statistics about the number of people who are admitted to hospital and what the outcome is.
- Review existing research on end of life care. This has been reviewed to identify key messages to inform research questions.
- The interviewing of older people living in independent care homes, their relatives and carers and also staff of the independent care homes, to find out what their views and opinions of end of life care are, what they see as barriers to person centred care and what could be done to induce change.
- An analysis of the material obtained and the preparation of a report of the findings.
- The holding of a seminar for all stake holders to review the information and develop a plan of action involving carers and service users.

It was agreed data would be collected from the following groups of people:

1. Older people living in independent care homes.
2. Carers or relatives of people living in independent care homes, or those whose relatives or loved ones have recently died.
3. Staff of independent care homes

Given the sensitive nature of the research there were clear process to ensure people knew about what the Project entails and what they were being asked to take part in. Consent was seen as a process and had three stages:

1. People were given information about the Project by independent care home staff, and asked if they were happy to have their names passed on to the researcher. They signed a consent form to say they agreed to this.

2. They were contacted by the research team to have a further discussion and if they were still willing, arrange a time for an interview. At the arranged time the researcher visited for the interview, went through the information leaflet again and asked for signed consent.
3. With participants’ consent, interviews were tape recorded and consent for this is included in the consent form. At all stages the voluntary nature of this research was made clear, as was the fact they could change their mind at any time, choose not to answer any question and that their decision had no consequences for their care etc.

It was recognised that taking part in this research project could cause people distress and lead some people to want to speak with someone about their relative or their own end of life care. A comprehensive range of support options was offered to people. It was made clear at the start of the interview that participants could stop at any point and for any reason, and if someone became distressed they were reminded of this option.

At the end of the interview people were left with a leaflet with contacts of people who they can talk to about the issues raised. The leaflet included contact details of local Cruise, Age Concern, the Alzheimer’s Society groups and The Carers Centre in Camchester, as well as the relevant Carers’ Support group attached to each care home.

The research had ethical approval from the Ethics Committee of the Faculty of Health and life Sciences at De Montfort University and Research Governance Approval from Camchester Health and Social Research Consortium.

¹ Seymour, J Witherspoon, R. Gott, M. Ross, H. Payne, S. (2005) ‘End of Life Care: Promoting comfort choice and well being for older people,’ Bristol, Policy Press/Help the Aged.

² Department of Health (2006). ‘Our Health, Our Care, Our Say’ (2006 London, Department of Health

³ POPPS ‘Partnership for Older People Projects’ – are Department of Health’s ‘Older People and Disability Division Projects’, the strategic aim of the Project is to test and evaluate innovative approaches that sustain prevention work in order to improve outcomes for older people

Sources of information

A total of four nursing homes and one residential care home participated in the study. The research used a mixture of individual interviews and focus groups.

Service Users

We interviewed 8 service users individually. All of these stated their ethnicity as White British.

6 were female and 2 were male.

3 stated that they had a religion (1 said Christian, 1 said Anglican and 1 said Methodist).

Average age was 82.6 years old.

The average time the service users had been living at their nursing or residential home was 2 years and 10 months.

Relatives

We interviewed 7 relatives individually; and 7 in a group interview, a total of 14.

All of these stated their ethnicity as White British.

10 were female and 4 were male.

For the individual interviews 3 of the 7 stated that they had a religion (2 said Anglican, 1 said Christian).

Average age was 65 years old.

The average length of time their relative lived in was 12.5 months.

All were either son or daughter of a resident (or deceased resident) apart from one who was a daughter-in-law (she was there with her husband, the son) and another whose mum and partner's mum had both lived in the home.

In the focus group 3 people were aged between 45-60 years old and 4 people were over 60 years old.

Their relationships to residents were as follows: three were daughters, two were wives and two were husbands (one being a widower).

Practitioners/Managers

We interviewed 18 individual practitioners and managers from the 5 nursing and residential homes.

11 stated their ethnicity to be White British.

4 described their ethnicity as Black African, 2 as Black Caribbean and 1 as Pakistani.

16 were female and 2 male.

Average age was 46 years old.

Length of service ranged between 7 months and 13 years.

Their average length of service in their current job was 6 years, 2 months.

10 of 18 stated they have a religion (4 said Christian, 3 said Roman Catholic, 1 Anglican, 1 Methodist, and 1 Mormon).

The researchers made attempts to hold a focus group for managers. Making contact with managers proved difficult. They were rarely available on the telephone and we often received no reply to messages. Eventually 5 managers indicated that they could attend. However on the day only one manager arrived. One other left apologies on the telephone.

Planning person-centred care

The understanding of residents interviewed for this project of arrangements made by and for them is as follows (they are in no specific order and all names have been changed).

Arthur stated that he had set out the funeral arrangements he wanted with relatives. The details were written down and in the possession of his daughter. He had also named the church he wants and the priest he wants to take the service. He said that the staff could talk to him about other end of life issues if they wanted but had not done so, up to that time.

Beryl said that nothing about end of life choices had been discussed with her. She commented that she could not remember things since a shock caused by the sudden death of her daughter.

Carol, a younger resident who is terminally ill with cancer had made detailed end of life plans.

Everything is in order. The funeral and everything is paid for. It's taken care of. **Resident**

Her immediate family are her son and her brother, "They fully support me".

Is planning for end of life care person-centred?

Deirdre said that her family would decide what happens to her when the time came. She did not want discussion with the staff team. She stated that she wanted to end her life in the home rather than in hospital.

Elizabeth said that her family would decide what happens to her when the time comes. She mentioned having a conversation with them about it but had not written anything down. She did not think that the care home staff knew what was important to her and that she would like it if they did. Elizabeth did not, however, feel that it was a good idea for people from the home to discuss these issues with new residents when they arrive. She said she had not discussed such things with her GP.

Fiona was sure that her family was clear about what she wanted stipulating how she should be buried. Staff from the home had not discussed end of life choices with her and she wondered if the question during the research interview related to burial. Nothing was written down and she had discussed nothing with her GP, although the GP was associated with her care home.

“Well the GP belongs to this set up, they tell you that is the area and therefore that is the doctor concerned. I had been with the doctor for many, many years, he knows my health better than they do.” **Resident**

Gordon knew the manager of his care home from his church. He had planned his end of life needs with his son and daughter-in-law and knew that they had been discussed with the care home staff who had ‘not really’ discussed them with him. This he did not mind ‘as long as they know’.

He did not know if these plans were written down. Gordon said it was his wish to die in the care home rather than in hospital.

Feelings about the care received

The vast majority of residents and relatives interviewed reported great satisfaction with the support and care provided by the nursing and residential homes. One relative told us her mother was very ill when she moved into the home but that now:

“She really is much better. We are pleased overall with everything here, we can’t fault it at all. Sometimes we feel sorry for the girls when they are a bit short staffed but as far as mum is concerned yes.” **Relative**

“Oh yes, yes, they look after you and you know you are involved with everything. ... You can have as many visitors in as you like. They are really, really good here. ... Oh yes the staff and everybody, they look after you so well, you don’t want to go home!” **Resident**

Thinking about end of life care

Many residents said they had either not thought about, or discussed end of life care before.

“I have never thought about it.” **Resident**

However two of the residents said they thought it was important to discuss end of life issues:

“Death is so sanitised now, death is so far removed from life it has been taken from us. (we) Need to be aware what end of life is and be prepared for it and have spoken with people about it.” **Resident**

The vast majority of residents and relatives interviewed reported great satisfaction with the support and care provided by the nursing and residential homes.

Residents not wanting to talk about end of life care

One resident told us she did not want to talk about the end of her life:

“Well I don’t think I want to until the time comes. I never think about it. I think I am not going to go yet, I know I’m not.” **Resident**

One relative explained that she felt her mother did not want to talk about it:

“She sits and reads the deaths in the paper, like most elderly do. But she doesn’t want to talk about it.” **Relative**

Asked if there might come a time to discuss it one resident responded:

“Well I would talk to her (daughter). But now at the moment I don’t think more about it.” **Resident**

“If you are ill then it is a different kettle of fish isn’t it? You would want some help if you were ill, but I never think about it.” **Resident**

Speaking with staff

Practitioners reported that someone from their home would speak to each resident (and/or their relatives) about end of life care:

“We have conversations with them, we do discuss about whether they want them resuscitated if anything happens to them, whether they want them to go into hospital, how far they want them to be treated.” **Manager**

One resident said he was certain that staff knew his plans:

“Yes, the manager and ... they know.” **Resident**

At a meeting of relatives, affirmation was given of the involvement of home staff in attempting to discover the wishes of their residents:

“Staff do ask if people want to speak about end of life care wishes, and people would like them to ask, and to know they are there to talk to about such things.” **Relative**

One relative knew that care home staff had recorded her mother’s wishes:

“Yes it was the charge nurse, the senior nurse.” **Relative**

However a different impression was given by most service users themselves. Since moving to the home one resident said that no one had talked to her about her wishes as she approached the end of her life, but she did not mind this saying:

“No, I don’t want them to. Anybody does that with me I have got it on my mind all the time and it doesn’t go away. I don’t like being over-powered with it.” **Resident**

Another resident said that there had not been any discussion involving her making decisions about her care with staff from the home. She felt that this was the role of the home:

“Well they are looking after us, we are in their care. So I don’t know that we have to make decisions, because they make them all, don’t they, for our benefit.” **Resident**

I don’t know, I have never given it a thought. ... I never think about that. I think about living not dying’ **Resident**

When asked if it would be useful for a member of staff to talk to her about these issues one resident expressed doubt saying:

“Why would it be useful? ... It has never ever entered into the conversation, it has never been spoken of, I don’t think they would...” **Resident**

Another resident was asked if it would be a good idea in the future for somebody from the home to talk to residents about preparation for end of life experiences. He simply responded “No”.

Relatives of another resident reported that they did not think staff had discussed end of life care with their loved one:

“No I don’t think there has because he would be telling us that. And he has not talked to us about the end apart from just saying, oh it is nearly Christmas I won’t be here then. That is the only time we have heard anything isn’t it, of his thoughts on that one. So I guess no-one has actually talked him through anything like that.” **Relative**

Speaking with relatives

Amongst the residents we spoke to there was a mixture of people who had spoken with relatives about end of life care and those who had not:

“I have got one son and two daughters. They can argue when I have gone, that is what I say, they can do their arguing when I am gone, and not when I am here.” **Resident**

Another resident said that although she hasn’t discussed end of life care with her son she felt there is a need to do so:

“No I have never talked seriously to him. We shall have to talk serious I know.” **Resident**

A different resident felt that end of life was a ‘nasty thought’ but accepted the need to confront the issue:

“Well the fact of it being so, becoming fact. It is approaching whether you like it or not and you have got to accept it. ... Oh yes, you have got to talk to them before about it and they are quite in agreement.” **Resident**

In some families, end of life issues are considered in depth over a considerable period of time:

“In our marriage we talked from early on about what we would do if something happened to one of us, cancer, stroke, Alzheimer’s. We had agreed we would care for each other as long as we could for the betterment of us both, that was important the betterment of us both. Then we agreed we needed to be very careful about where they would go but also recognised we needed to make decisions before it was too late.” **Resident**

However a further barrier to these discussions was raised by one resident:

“Well I have with my family but we don’t get on that subject now, they don’t like talking about it. ... They can’t get thoughts of me going in their head. ... They don’t want to think about that no, they say Shut up mum you’re not going yet, you’re not ready’. ... They say ‘Oh Nan we are not on that subject yet’.” **Resident**

Speaking with GPs

One resident was not certain if his GP knew of this wish and was unsure whether this was important: “I should imagine so, I don’t really know. Would it make any difference?” **Resident**

A relative of a recently deceased resident said:

“Yes she discussed it with the GP. She was ready, she was in here up until July of this year for three years, and she had said before she even went anywhere she said you know I wish I could go now, I am ready for going, I am weary. And she was, she was really tired but her brain was so active. She came in and she said I am going to do it but I hope I am not going to be around for long. She had lost everybody who was close to her apart from me and she was anxious that I didn’t have to take her care on at home.” **Relative**

“But she had said to the GP I don’t want to go on forever, I don’t want resuscitation and I don’t want to be sent into hospital. Because she pointed out that if she found her laid out she had an obligation to get her into hospital if she thought that it wasn’t going to be like that. She was really very nice about it but mum was insistent that they didn’t do anything for her.” **Relative**

She was certain that the GP had written the instructions down:

“I am sure she did, it is certainly written on her notes here and I am almost certain that it was on her notes at the surgery because mum had made it so very clear.” **Relative**

Relatives involvement in decision-making

Two residents explained that their relatives would make important decisions about end of life care on their behalf. It is important to note that they were both very happy for this to be the case. “I have got a family and they will decide what happens to me when the time comes.” **Resident**

Some relatives spoke about conditions such as dementia which make the participation of the resident in end of life decision making intensely problematic. For example when the time came to make a decision about moving to a nursing home, one husband of a woman with dementia said:

“I realised I had to make that actual decision without any input from her.” **Relative**

Funeral arrangements

It is notable that a number of service users initially interpreted end of life care to mean planning for funerals. This was despite the Project’s previously circulated information which clearly stated that it was about care at the end of life. This was one area about the end of their lives that the majority of residents had made decisions about:

“I have told my family what I want, where their mother’s ashes are buried and I want to be right at the side of there and I will be with her then and I will be happy.” **Resident**

Writing down decisions about end of life care

Only one of the residents we spoke to told us that she had written down decisions about end of life care. However it was unclear if these extended beyond the subject of her funeral and will:

“Yes my daughter has got it. The church I want to go to and the priest I want to take the service.” **Resident**

No one we spoke to had advanced care directives.



The barriers

One of the most considerable barriers to choice in end of life care is the reluctance of many practitioners to raise the subject with residents. All the homes had care-planning paperwork that includes end of life decisions. This paperwork is supposed to be filled in when the resident first moves in.

There is a paper that [name of company running the nursing home] use and that is one of the first pages in the thingy and it is called end of life wishes. Some people choose to say openly 'oh I want this to happen' or 'I want that to happen', but some people they don't want to discuss it so they read it and sign it and they don't want to discuss it at that point. But you can only go back to it when the resident feels able to talk about it. ... So what I tend to do is briefly skirt around the issue and if they choose to talk about it fair enough, but if they don't want to talk about it is perfectly within their rights. **Practitioner**

Reluctance of staff to talk about end of life

“It is very difficult when you don’t know them, it is easier when people have been here a little while and you have got to know them a little bit better. But I will ask the question and I will also feel the ground, if I am doing the general pre-assessment I will probably leave that question until a little bit later on in the assessment so at least you have got a little bit of a feel for how that person is feeling at the time.” **Practitioner**

However staff also recognised that such discussions were important and should not be delayed too long:

“I have admitted people into care and two days later they have died and we have not known what needs to be done. So I am very conscious about that and we try with relatives or significant other people to establish what their wishes are, what the resident’s wishes are, and asking them themselves, but it is finding the right time to do that and doing it in a sensitive way, and to establish if people want to spend the rest of their days here or do they want some interaction with invasive therapy with the hospital service.” **Practitioner**

A relative gave her impression of the process, clearly understanding why it is felt to be important:

“Oh yes, that was done on the day he came, they (staff from the home) sat down with us and asked for all the details. ... But he had not discussed the actual process before that at all. Obviously it is new to us as well, I suppose until a crisis happens you are not brought to attention are you, unless somebody does actually sit with you and talks it through.” **Relative**

Staff from most homes described a policy of senior staff such as managers or senior nurses having such sensitive discussions with residents and relatives about end of life decisions. Junior staff, or care assistants explained that they are not required to raise these issues (and in at least some cases have been told not to do so). These junior staff made the following comments when asked if they spoke to residents about the end of their lives:

“I don’t know, I have never asked them. It is a thing I wouldn’t ask them because I don’t think they would like to.” **Practitioner**

“I wouldn’t no, because it would probably make them more upset so I wouldn’t. It depends what situation the people are in as well, some of them do talk but some of them just don’t.” **Practitioner**

“It is something that frightens us all not just the residents but everybody because to be honest nobody wants to die, especially for residents because they know they will and they are going to die. So it is really hard for them and I don’t want to talk about it around them.” **Practitioner**

“Well some are really afraid and you can tell they are afraid, so their own fear would not allow me to mention anything like that. ... And in that case I wouldn’t want to upset them any more than what is absolutely necessary.” **Practitioner**

A nurse considering what could prevent care being person centred at the end of life said that there were sometimes problems because of the anxiety practitioners feel in raising the subject with residents or their relatives.

Staff fear asking them about it, putting it off and then maybe not letting anybody else know until you go through the paperwork. And sometimes the relatives themselves will say, ‘oh don’t talk about that’. While we do try to take into account the relatives’ wishes as much as possible obviously our main focus has got to be the resident. **Practitioner**

Finding the right time to discuss end of life wishes

There was a widespread reluctance among staff to raise sensitive end of life decisions with residents and relatives when the resident first moves in, as they felt it was not an appropriate time to raise such issues, before relationships have developed:

“We do do the basic care plan within 48 hours of them coming in. But things like end of life care we have a specific page in the care plan for death and dying, and so we tend to get to know them a little bit better and speak to the relatives and try to formulate something they are happy with.” **Practitioner**

“It is not appropriate always to bring it up then (when a resident first moves in) although it might be easier if you could. You might find someone gradually deteriorates and then you are left asking a question which if you had asked before when it wasn’t really a problem then it might be easier to do. ... There is something (in the paperwork) about what do you feel about dying? I think most of us skip past that because if someone has just come in I don’t really want to talk about that in that way.” **Practitioner**

“It seems a very strange time to be doing it but we actually need that information, it is one of the things. It is in our regulations that we have to have information about end of life. So we actually talk to the residents and the families usually within 48 hours of admission to get their wishes known.” **Manager**

As stated earlier in this report many residents are reluctant to talk about the end of their life, but this is not always the case:

“Well the fact of it being so, becoming fact. It is approaching whether you like it or not and you have got to accept it.” **Relative**

“I always think well if it has got to be seen to, you have got to speak about it. It is no good waiting.” **Resident**

Sometimes scant information about any general wishes, including even where burial should take place has been communicated to relatives. This can be particularly important if later there has been deterioration in ability to make an informed decision due to the effects of dementia for example.

One relative experienced the need to make very difficult decisions about her mother:

“It wasn’t until she had been here about three months maybe, two or three months, when she had had a water infection and that was when I was approached about resuscitation, at which point again I felt I had to make the decision. At that point I did say resuscitate within reason, not fully understanding what it involved, I thought it just meant the kiss of life, and at that point I felt she had got some quality of life left and that it would be worth resuscitating. But then after she had had a stroke it was obvious that she wasn’t going to get any quality of life back because she couldn’t swallow, then I had to sort of reverse back and say to the staff, who were absolutely wonderful, no resuscitation, if it is her time to go then it is her time to go. But it was difficult to make that decision.”

Relative

This decision was recorded in writing by the staff.

The emotional struggle that this individual experienced was reflected in the final decision she had to make as her mother’s condition deteriorated. The issue of whether to admit to hospital or not was a key factor. At this time she recalls being well supported by the staff and GPs: “Because she couldn’t swallow she was getting no fluids into her and this was when I discussed with the first doctor about whether we should send her to hospital and put her on a drip, and [Name], the nurse, was involved in all that. We discussed that twice over a period of a couple of days or so and I had to make the decision did we send her to hospital or not. It was again, I think that one threw me into a complete, I was here on my own then and I had to make that decision, do I get an ambulance now and send her or not. That was probably one of the worse points but again the doctor and the staff

were very reassuring, not telling me what to do but advising me that it would be better to leave her here rather than, we didn’t even know she would have made it to the hospital. So that was possibly one of the worse times but again the staff and the GP were there to support and to advise. They left every decision to me, they didn’t make the decision for me, it was left to me to make that decision, but yes I can’t speak too highly of the GPs and the staff, very, very professional.” **Relative**

The impact on families and carers of end of life planning

Although the focus is ostensibly on the resident, major stress, often associated with guilt is sometimes experienced by the extended family. They may often have been closely associated with the care of their loved one before hospital and then nursing or residential homes have been mooted: “Giving support to the families, I think in all of this people sometimes forget about the families.” **Manager**

A member of staff could recall instances where there had been disagreements between relatives and residents about end of life issues. In supporting the families through these difficulties it was felt by the interviewee that a number of factors were important: “From what I recall yes. I do know we have had families who were against wishes, from what I recall it was sorted out not really by us but by a medical, by GPs, generally communication, education and just basically getting together and talking about things.” **Practitioner**

A carer described a support group that provided a valuable service to carers and relatives and was also a useful source of communication for staff. It meets monthly with staff and managers. Carers raise issues and receive updates. The group: “Builds confidence and shows how we are working to a common need, there is a clear interchange of ideas and relatives feel listened to.” **Relative**

Relatives making decisions on behalf of residents

A home manager pointed out that the practice of family members making decisions on behalf of service users, whilst still common, should be seen as out of date:

“I think that is still an old fashioned thing in nursing homes where the resident wasn’t asked but the families were asked and the families’ wishes were paramount. I think that is changing but I think it is taking some time.” **Manager**

This interviewee also cited an instance of staff allowing the wishes of a resident to be overruled by her relatives. She was very unhappy about this.

The interaction with, and important role of relatives in the decision making, is revealed in the interviews with practitioners. However there was much less mention of the participation of residents themselves, for example in relation to completing paperwork:

“If they (residents) are capable of signing, if not it would be the next of kin who would be responsible for it.” **Practitioner**

“When they move into the nursing home, when they are admitted, the relatives have to fill in certain forms. And one is if they are here or if have to go into hospital and they are not really going to pull through do you want to be resuscitated. And that is the form that relatives have to fill in.” **Practitioner**

This practitioner explained that the form used is not just for relatives but also for the resident themselves. However relatives often take the lead:

A home manager pointed out that the practice of family members making decisions on behalf of service users, whilst still common, should be seen as out of date.

“It is mainly the ones who aren’t well enough to decide for themselves. The RGNs have more input with that, I just get to know from what the residents’ families say to me, they say ‘we don’t want them resuscitating if it comes to that’. A lot of them if they are quite elderly, they will say ‘I don’t want to go into hospital either, if they are going to pass away I would rather they passed away here in the home with people around them they know and trust’. That comes through quite a lot, ‘I don’t want them to go back into hospital’.” **Practitioner**

An interview with a relative gave an extremely worrying example of this. The relative spoke of paperwork about end of life decisions being filled in by her family without discussion with the resident. She told us that the family had not raised the subject with their mother, nor indeed their father, before filling in no resuscitation paperwork, and that she was unsure whether staff had spoken to the resident about it. There was no suggestion that the older person was incapable of doing this for themselves: “I don’t know whether they (staff) have discussed it with her but we ourselves have signed a form, a ‘no resuscitation.’ ... Me and my sisters have spoken about it, we have not discussed it with my father, he is 87, and we decided we didn’t want resuscitation. But I don’t think it has been discussed with her (mother) because I don’t think she would understand. ... We haven’t spoken to her because death to my mother is a bit of a no, no, she doesn’t want to know about it.” **Relative**

A nurse stated that she had never seen disagreements between residents and their relatives about end of life care but had wondered sometimes herself about decisions taken:

“I have seen some situations of which I personally think maybe somebody would need that and then the GP or the family would say no there is no quality of life. Do you see what I mean? But because you are just a nurse you feel what am I going to do?” **Practitioner**

The same individual felt uncomfortable in expressing her views in such situations:

“It is very difficult, it is very difficult. Yes it is very difficult to voice your opinion, to say no just try this, or no it is maybe just a normal chest infection let’s try antibiotics. Because there are some people you think, oh my God, maybe they could have tried an antibiotic and she would have been well, or maybe they could have tried taking her to hospital and get some intravenous antibiotics and she would have been ok, instead of just looking at somebody and judging, no there is no quality of life, she won’t pull through, she will die, and just leave her like that.” **Practitioner**

However a manager from another home discussed conflicts between what a resident wanted and what the resident’s family wanted in very different terms: “We would explain the situation, that while that resident has got consent capacity then we really need to discuss it with that person. But we would do it in a way that wasn’t, ‘now then when you die what do you want to do?’ It wouldn’t be that sort of attitude in which we would do it. We would ask the family to be present as well if they wanted to be and also we ask them if they wanted to speak with the GP, if it was definitely a suspected end of life get as many people involved.” **Manager**

Staff attitudes

One resident was quite clear that she saw staff attitudes as a barrier generally to person centred care at the end of life:

“Attitude, the attitude of some carers is wrong, they like to boss old people about and say we are in charge, they are not, they are doing a job. And the carers need their service because at the end of your life you are not as active as you used to be, you can’t do physical things like you used to do and you can’t do mental things like you used to do, you need a rest.” **Resident**

Generally speaking however, residents were happy with the standard of their care.

I think we should have our opinion listened to more. Some of our carers have the misconception that they are bosses, they are in charge, and they are not, they are doing a job. **Resident**

These girls here are run ragged, I have seen staff cry because they don’t feel they have done justice to us, they should never have to feel that way. ... They finish up in tears nearly, especially new ones that come along. **Resident**

Funding and staffing levels

One nurse explained a further problem about staffing levels and personal care. Although each resident would have two staff allocated as key workers, shift patterns and working practices would effect the time that might be spent with each older person:

“They don’t realise that there are some times when it is critical, maybe somebody is dying and she needs somebody to sit with them. ... I am telling you the truth, you won’t have somebody sitting there until they die, unless maybe the family will sit with them there and then you are just peeping in to see how they are doing. You give the little, little care you can give really but not specifically assigning somebody to sit there and hold their hand or talk to them, it is really impossible.” **Practitioner**

The nurse felt that this was an important issue leading up to a death and failing to provide such a level of care was not good practice. She also believed that budgetary factors could be involved as well:

“We can’t even get extra effort because if we get an extra person all they are looking at is their budgets, you see, because it is extra expense to pay that person who has come in. But they don’t look at somebody’s care as well as this.” **Practitioner**

She had experienced this situation more than once:

“I have, a lot of times I have experienced that but unless you are ... oh my God, she will go any time, you are doing some other things, looking after some other people, but still you have to run and go and see them, ‘oh is she still breathing?’ But you can’t sit with them which is quite strange.” **Practitioner**

A manager also spoke about the importance of this personal support at the end of life:

“We could always do with more resources, we could always do with someone additional to sit with people in the end of life stages, I don’t believe that anyone should be left on their own, and the general run of the building, that can be a problem.” **Manager**

Not all practitioners experienced difficulties with resources around staffing:

“I have got a very good manager and the company as a whole. I can’t speak for anybody else but maybe for the independent singular homes where the resources are strapped more, that could have an impact for them, but I can’t really speak for them.” **Practitioner**

Agency staff

The issue of support from staff who were familiar to residents, as the end of their lives approached, appeared from the interviews as being variable between homes. One nurse noted:

“What we have tried to do when there is end of life is we try to put staff on which they know well and can look after that individual person. And until recently the hospice would pay eight hours a day of that wage as well to do that as an extra support, more so probably for the smaller individual homes that didn’t have the resources and couldn’t afford to put somebody on.” **Practitioner**

The data also revealed that agency staff were rarely used in the nursing homes that were part of this project and that bank nurses were able to maintain a more person centred approach. Bank nurses are employed directly by the home on an ad hoc basis and are often people who have previously worked on a regular/full-time basis at the home. They were used by most establishments:

“I am very fortunate I have a bank of care staff and a bank of nurses. ... They are my staff and they work for me but they only work when they are available or when I need them. So I have about six nurses who are bank and about six carers who are bank so if somebody goes off sick.”

Manager

The data also revealed that agency staff were rarely used in the nursing homes that were part of this project and that bank nurses were able to maintain a more person centred approach.

“They are trained by me and they belong to me but they also work somewhere else. So some of them might work for an agency somewhere else but I don’t pay them agency rates. Also because now we are a big company we can call on our sister homes.” **Manager**

A manager from a different home said that agency staff were used more regularly:

“We don’t have a lot, if we do use agency, we try and use the same one and ask them if they can send the same people. Because we have got a lot of carers who have got young children and the child can be ill and they ring up and say sorry I can’t get in. I do try and get somebody who has been before so they know the home and they know the residents. At the moment we have not used agency for quite a while.”

Manager

She outlined the reason why:

“For example somebody from an agency might not know people’s background, might not know some of the decisions they have made.” **Practitioner**

I can tell when I walk in if agency staff are on. My wife can not see and can only recognise familiar sounds, so new voices can disturb her – the importance of regular staff can not be overemphasised. Regular staff are best for constant and appropriate supervision and care. **Relative**

Relatives from one particular care home (where no staff were interviewed) had strong feelings about the use of agency staff, and the impact on the care given to their loved ones:

“When I was here the other day there was an agency support worker was on and I hadn’t seen them before, and he wasn’t aware of the fact that [her husband] was totally deaf and that he can’t communicate. And then he said to me are you going to feed him, and I said ‘No he can feed himself’, and he said ‘Oh go on give him a treat’. And I said ‘I am sorry, while he has got his independence, alright it is finger food, but I am not going to take that away from him, he can feed himself’. And I found that quite unacceptable because he should have known and he was shouting to him at the top of his voice, and I said, ‘He can’t hear you’, and I thought he should have known that. And I said ‘Is this the first time you have been?’ and he said ‘Oh no I have been before’. But I think it is something just at the moment we have got to accept.” **Relative**

“I can tell when I walk in if agency staff are on. My wife can not see and can only recognise familiar sounds, so new voices can disturb her – the importance of regular staff can not be overemphasised. Regular staff are best for constant and appropriate supervision and care.” **Relative**

“When agency staff are on my mum has sometimes no teeth in, she is a poor eater any way and with no teeth ... Since the change over in January in a short time three hearing aids just disappeared and she is really fretful, she needs her hearing aid and when she hasn’t got it she is really disorientated she is really agitated. So when things happen like that it is really distressing and it happens more when agency staff are on.” **Relative**

“Yes it is difficult at the moment as there are such a lot of agency staff on who don’t know the residents. They are agency staff and only here for a short time, it is harder to have those relationships. It is harder to have that level of understanding of what people want and who they are.” **Relative**

GPs

A practitioner outlined difficulties that could arise if all the authorising signatures are not obtained on 'Do Not Attempt Resuscitation' paperwork. In this, the signature of a GP is the necessary endorsing factor:

“The worse thing for me is when we know that person wants to stay here and we might not have the one signature that we need, or we rang the GP co-operative on the night time because of a pain relief issue or something like that, and the next you know a 999 is knocking at the door which does happen. And sometimes it is very hard to stop them taking her away because of their legal obligation of being called out, that is the worst thing for me.”
Practitioner

This nurse acknowledged that the service user's GP would inform the home of any end of life plans or living wills that they were aware of. Problems could sometimes arise because of other issues however:

“Sometimes, a lot of our residents might not know their GP very well because they have been reallocated because of the location. The other thing that we would do is if we know the resident's wishes then we would have a form that we have as part of the end of life care, we have been using this one for a while, about hospital admissions and do not resuscitate. But they have to be done with the residents, with the family and with the GP, so that is another angle of it as well. We have that plastered on the front of the nursing notes so we know if it is in the middle of the night and you open the notes, what should I do, oh it is quite clear what I do here.”
Practitioner

The out of hours cover system now used by GP's was also seen to cause difficulties:

“We had the lady who was 100 and she was taken into hospital one night and I was sorry she went into hospital.” **Practitioner**

The importance of pain relief was clearly acknowledged in the interviews and problems leading to admission could sometimes be avoided with support:

“The staff there (the hospice) are excellent and they will actually advise whichever GP might need a bit of advice on what specific pain relief that person should be trying.”
Practitioner

As to whether the system worked in the opinion of this nurse:

“It does as long as everybody signs it. The issues we have are when they have a DNAR (Do Not Attempt Resuscitation) in hospital and they are on transference to us, the DNAR does not cover anything from the hospital.” **Practitioner**

The importance of good working relationships between the relatives, the home staff and the doctors is emphasised as being crucial:

“On the whole it has been good, there has been occasions where we have practically come to blows about the care that somebody should receive towards the end of life. Because they want them to go into hospital and sometimes I really don't see the point unless they are going to give them some drastic treatment. I don't see the point of somebody being shipped half way across the city for something that we could do here really. But on the whole my experiences have been good. We have built up relationships with GPs and they tend to listen to us.” **Manager**

The manager of a care home spoke of a related problem:

“And the other issue that arises is if a resident has gone into hospital they may have a DNAR notice in hospital that doesn't apply when they come back to the nursing home, so you have to start all over again.” **Manager**

This lady died in hospital having spent six months in the home:

“At night things are different, and if someone is 100 their relatives are all in their 60s and 70s and weren't prepared to be at the end of the phone. And it was not known whether it would be something that would be treatable in hospital. If things happen during the day when the GP can visit there are a lot of problems solved really.” **Practitioner**

Hospital or nursing/residential home?

A key barrier to choices in end of life care spoken about by interviewees was people who choose to die at a care home being admitted to hospital at the end of their life. There were examples of successful decision making resulting in deaths occurring at nursing and residential homes:

“Because sometimes there comes a point where you can't keep giving someone antibiotics, you can't keep sending them to hospital, and it is at what stage do you make that decision? I don't think anybody here has got it but we have had residents in the past who have made a living will and they have categorically refused to go into hospital and have any more treatment. They have decided that is enough and they discussed that with the GPs as well.” **Manager**

“We have had probably six or seven in the time I have been here (seven years) who have made that decision, that they don't want to go into hospital and that has been followed through.” **Manager**

Having the correct paperwork completed is an essential element of this:

“It depends when the paramedics come and they find that person is still breathing, they still have life in them, I think we have had one case where the paramedic came and the lady is still breathing, and because the resuscitation consent was only signed by the family she was taken to hospital because it was not clarified by the GP.” **Practitioner**

The primary issue was seen as giving older people the choice, and crucially then ensuring that their choice is respected:

“To give that person as much as we possibly can how they have told us they want their end of life to be. So if that is staying here, some people do choose to go into hospital, they don't always want to stay in their care environment. And some people chose to go to [name of hospice], which is our hospice just down the road, because they see the hospice as the place where you need to be to die. I think that is a sort of age thing as well.” **Practitioner**

Some older people said they hoped to stay in the care home at the end of their lives:

“I would rather stay here if it is possible.”
Resident

Being moved to hospital or even to a different care home had not occurred as a possibility by one person:

“No I have not thought about it.” **Resident**

A care assistant felt that most residents favoured not going into hospital at the end of their lives:

“Not mostly in hospital, they wouldn't like to be in hospital. Some of them at home or with their family and stuff.” **Practitioner**

The importance of good working relationships between the relatives, the home staff and the doctors is emphasised as being crucial.

A lack of prior discussion and planning can lead to difficult decisions as the end of life approaches.

One member of staff felt that only a very small proportion of relatives wanted hospital treatment for their relatives except in an acute situation:

“You are still going to get relatives who want what is best and there are relatives who still think if they go into hospital it is going to be best, but that is probably about 5%. The vast majority who haven’t been what we call acute, who haven’t suddenly collapsed and had to be rushed in, the vast majority in all the time I have been here have been nursed here until it is the end of their lives.” **Practitioner**

As referred to earlier in this report a lack of prior discussion and planning can lead to difficult decisions as the end of life approaches:

“I would say March this year we had an instance that we had a lady who we had to ring 999 for, the lady was nearly 100. And when they all got here, and her daughter was here, they were just about to take her off to hospital, and her daughter said ‘No I don’t want her to. Is she going to get better? No, leave her here, I want her to die here where she is loved and cared for.’” **Practitioner**

A relative was surprised by the reaction of one practitioner he had known for some time, towards end of life.

“She absolutely agreed with me, very forcibly, and because of my mother’s personality she said ... She didn’t say ‘I wouldn’t dream of resuscitating’, but she said ‘I would ... I will tell you what she said, ‘I would take a walk around the building before I resuscitated your mother’, and I was astonished at that. So she has obviously seen exactly what I was saying.” **Relative**

Our research revealed some situations leading to very traumatic incidents:

“I mean for instance we’ve had one case with a lady who was discharged to a nursing home at lunch time and for her journey from the hospital to the nursing home had a DNAR form faxed through to the ambulance service, and she was fine, she had her tea, and then about five minutes after she’d eaten her tea she became quite poorly, she became quite breathless, so the staff rightly dialled 999 and she obviously she’d said that she wanted to spend her end of days in the nursing home, and her son was present and asked that she should spend her end of days in the nursing home. The paramedic came and resuscitated her in front of the family because the DNAR form from the morning did not stand (it was only for the journey). So there are huge issues around, I think, about the basic rights of service users.” **Manager**

One nurse thought the attitude of a particular GP was a problem:

“We have got one GP who if it is something which I think might be quite trivial he might say well ring 999 for an ambulance, he doesn’t respond appropriately always.” **Practitioner**

A manager said:

“Yes some of them go to hospital. ... Not that much I wouldn’t say. We can accommodate if people want to be here but obviously with some things you have no choice have you really? If they need medical attention that they can’t provide here.” **Manager**

The interviews revealed that such a situation could lead to the resident then dying in hospital:

“A lot of them if they are quite elderly they will say ‘I don’t want to go into hospital either’, if they are going to pass away I would rather they passed away here in the home with people around them they know and trust. That comes through quite a lot, ‘I don’t want them to go back into hospital’. Often people will say, ‘Oh before they went into hospital they could do this but they have been in hospital for six months and now they are bed-bound and they can’t walk because they have just been left. I know hospitals are busy but it is a vicious circle sometimes that the families don’t want them to go back into hospital because there are a lot of issues they have had in the past. They would prefer them to stay with us if at all possible.” **Practitioner**

Bed blocking

A practitioner commented that such an issue was also a concern to her. In the instance she referred to, a resident had, she felt been placed in a particular home in order to free a hospital bed without taking into account the inconvenience created for her elderly husband, who did not live near. This particular member of staff felt that social workers bore some of the responsibility, taking a short term rather than longer-term view: “And I think sometimes it is all about bed blocking, (they think) we need to get them out into a home as soon as possible, any home will do, not thinking about, well really they need to be near the family so the family can visit.” **Practitioner**

A concern identified by one manager related to perceived policies of moving older people on to create bed space on hospital wards:

“I think what we tend to be getting in nursing homes, it is a horrible thing to say, are the ones that the hospitals don’t want anymore and they are really at the end of their life. And we have had people come in who have probably been with us for two weeks and we have even had less. We have had someone come in who has been two or three days and to be quite honest that person should never have left hospital. You become very cynical in this job and you just wonder is it just a bed clearing process. They shouldn’t really have left hospital because the journey was too much for them.” **Manager**

A manager spoke about concerns that people being referred to the home are closer to the end of their life than in the past. This factor can make it difficult to build a relationship with the resident and to offer a person centred service.

One practitioner said that she approved of rapid referrals to care homes from hospital as long as they were appropriate:

“When you have got somebody in a (hospital) bed and they are bed blocking and we have got a room here it is daft that we can’t try and hurry the system up or change something around. Because it is to their advantage to get the empty beds because they are always saying ‘Oh we haven’t got a bed for you in the hospitals’ aren’t they?” **Practitioner**

However, the need to establish contracts between social services and the home was seen as a source of delay to some admissions.

People being referred to the home are closer to the end of their life than in the past. This factor can make it difficult to build a relationship with the resident and to offer a person centred service.

Fear of blame

Several practitioners expressed concerns that if they followed residents wishes about not being resuscitated or taken to hospital at the end of their lives, this could have negative consequences for the practitioners involved. They referred to being blamed for not making every effort possible to preserve life:

“That is happening more and more regularly since Harold Shipman. I will tell you one instance of a woman who had an aortic aneurysm and it popped, she must have gone about five minutes before they went in to check her, so they dialled 999 and got the ambulance out. And the police came because it was unexpected and one little comment by one of the two young paramedics who came said ‘it doesn’t look like they made much attempt at resuscitation’. They sealed the room off with crime scene tape, they took forensic evidence, they interviewed everyone on staff at the time. And this woman had already said she didn’t want resuscitating and having found her having gone, they didn’t know how long she had gone. And that was a really, really difficult situation, really difficult. We were all interviewed, I felt like a criminal.” **Manager**

The consequences for staff in circumstances when deaths occur could sometimes, one nurse felt, cause anxiety and effect confidence. A nurse described colleagues experiencing criticism after they had allowed an elderly resident to die naturally with the implication that there had been neglect. This nurse also did not feel that there was a good working relationship with the GPs associated with the residents in the home where she was working:

“GPs, they seem to be very busy, I don’t know if it is because of the shortages or whatever but they seem to be very busy. Even how I look at things, some of the things they are things which you can avoid if you work as a team with the GP. Like if you plan how somebody is going to die and if those people, as a rule it is easier if they have been seen maybe in two weeks time then it is expected, or the GP is aware that somebody was not well, I feel if we worked as a team it was going to be better.” **Practitioner**

A home manager outlined the situation that would occur if a person died, having not been seen by a GP for two weeks previously:

“If someone dies in a home who hasn’t been seen by a GP within the past two weeks it is an unexpected death and we have to ring the police, and they have to go to the coroners office. And the coroner then decides if there is to be a post-mortem or not. It is quite traumatic really. **Manager**

Particular problems can arise for night staff who work at a time when many deaths occur. It was implied that they might feel particularly unsupported in making the correct decisions

The anxiety of staff and sometimes paramedics and the police service to ‘cover their backs’ could lead to sometimes very distressing scenarios. As outlined by a nurse:

“I don’t see any dignity there, when somebody has had a quality life and then at the end you throw them on the floor to resuscitate them. What for? It could have been avoided if they had been visited by their GP and you plan things. We are forced to do that because you don’t have anything to show to the paramedics or the police that says this is the plan, this person should die here. They will ask you what did you do? The first thing when you saw this one was dying what did you do? They will caution you if you see what I mean. Like if it was planned.” **Practitioner**

The nurse stated that such a situation had occurred ‘several times, several times’. This individual also went on to say that even if a resident had personally signed a DNAR form and was mentally capable of doing so, if there was no signature of a doctor, they would resuscitate and ignore the stated wishes. Such an action would be seen as in defence of their own interests:

“It has happened before depending on who is working as well, because if you are not comfortable you have to just send them to hospital.” **Practitioner**

One nurse expressed considerable discomfort in the way end of life plans are devised at her care home. This demonstrated a lack of confidence in the system that implied a possibly different experience for residents and staff in this care home compared to others.

Particular problems can arise for night staff who work at a time when many deaths occur. It was implied that they might feel particularly unsupported in making the correct decisions:

“There may be differences in that during the nights you are alone, you don’t have many people around you to confer with. And if a situation arises and it is not made initially clear what to do with this particular resident or patient then you have to make that decision, or having to call someone out to assist you in the decision making, or making that decision there and then as to what to do. Sometimes you might end up making the wrong decision I would say because you think oh I don’t know what to do. And because you have not discussed this issue before or you have not met relatives and got information or all the facts. Then you say well I think we will just take them to hospital and they end up in hospital and you find out it is ... and you might just as well have left them here.” **Practitioner**

I have had staff ring me up at three o’clock in the morning and someone has been found dead in their bed and they have just been absolutely distraught, ‘what do I do, I don’t know what to do’. And it is very, very upsetting for everybody. And yet the GP can’t see every resident every two weeks, that is not a reasonable thing is it? **Manager**

One important fact is the relative absence of residents from black and ethnic minority groups in the care homes included in this study, and so little experience of the issues from some staff.

Accidents such as fractures and consequent acute emergency admissions could lead to residents dying in hospital during treatment. This could apply even if the resident has a DNAR notice. These acute conditions may require emergency treatment and a decision will be made by staff whether to call for paramedics, as outlined by a home manager:

“It is something that is unexpected so they do have to use their professional judgement then, so ok in my judgement I am going to call 999 because this isn’t what was anticipated.” **Manager**

Also, a further issue was that older people who had initially wished for no treatment sometimes changed their minds. The nurse who made this comment added that staff would be as flexible to these changes, doing ‘as much as we can do’:

“But people also change their mind at the end of life as well, this is what I see as my ideal, this is what I want to happen, we get there and they change their mind, or their family try and change their mind. It is not always smooth planning, what you thought three months ago would be good for isn’t two weeks later.” **Practitioner**

Cultural differences at the end of life

One important fact is the relative absence of residents from black and ethnic minority groups in the care homes included in this study, and so little experience of the issues from some staff:

“There is one guy here now and he is Chinese but there has not been any Muslims. I think they tend to look after their own don’t they? I have not experienced it really.” **Practitioner**

“It depends what the cultural difference is, you deal with it as and when. I haven’t met many cultural differences with the residents, most have been people who have lived in or around the area for many years. But we do have cultural differences between residents and staff, it is the staff who have cultural differences not the residents.” **Practitioner**

“We haven’t had any experience here, I have had it in the past when I was nursing in the NHS, but we haven’t had any here that I can recall. Oh we have, at the time it was a bit of a panic, it was a Jewish gentleman that passed away and we had a bit of a panic trying to find a Rabbi. But we have had in the past, not recently, various teaching and educational sessions on different cultures and how to deal with different cultures. But in general because it is not particular. At the moment if anything happens then we would probably need to refer to the policy book, generally phone round for specific advice or advice from the family hopefully.” **Practitioner**

When I first started, that did cause some problems mainly because elderly peoples approach to ethnic minorities it is not something they have been used to. However the nurses care and the carers care has proved itself, they have an empathy for the elderly that a lot of English people don’t have, people who were born in this country. **Manager**

In contrast to residents there was a strong representation of staff from ethnic minority groups working in the care homes. One manager acknowledged that all residents in the home were white while staff were almost exclusively from African countries. This was acknowledged as having raised some issues in the past. The manager felt that these problems had been resolved:

“Even when we had our first inspection report they have always put in that the residents would always say how kind and caring the nurses and carers are and how well they are looked after. And how they also have a very positive outlook on life as well and they smile and they are approachable. So there isn’t any conflict between their culture and our culture.” **Manager**

“It is a fact of life isn’t it that we are a multi-cultural society and nursing homes for whatever reason basically the vast majority of staff that work in them are from another country.” **Manager**

Not all members of staff spoken with had attended cultural awareness training, however some did and also that they had learnt much from the training:

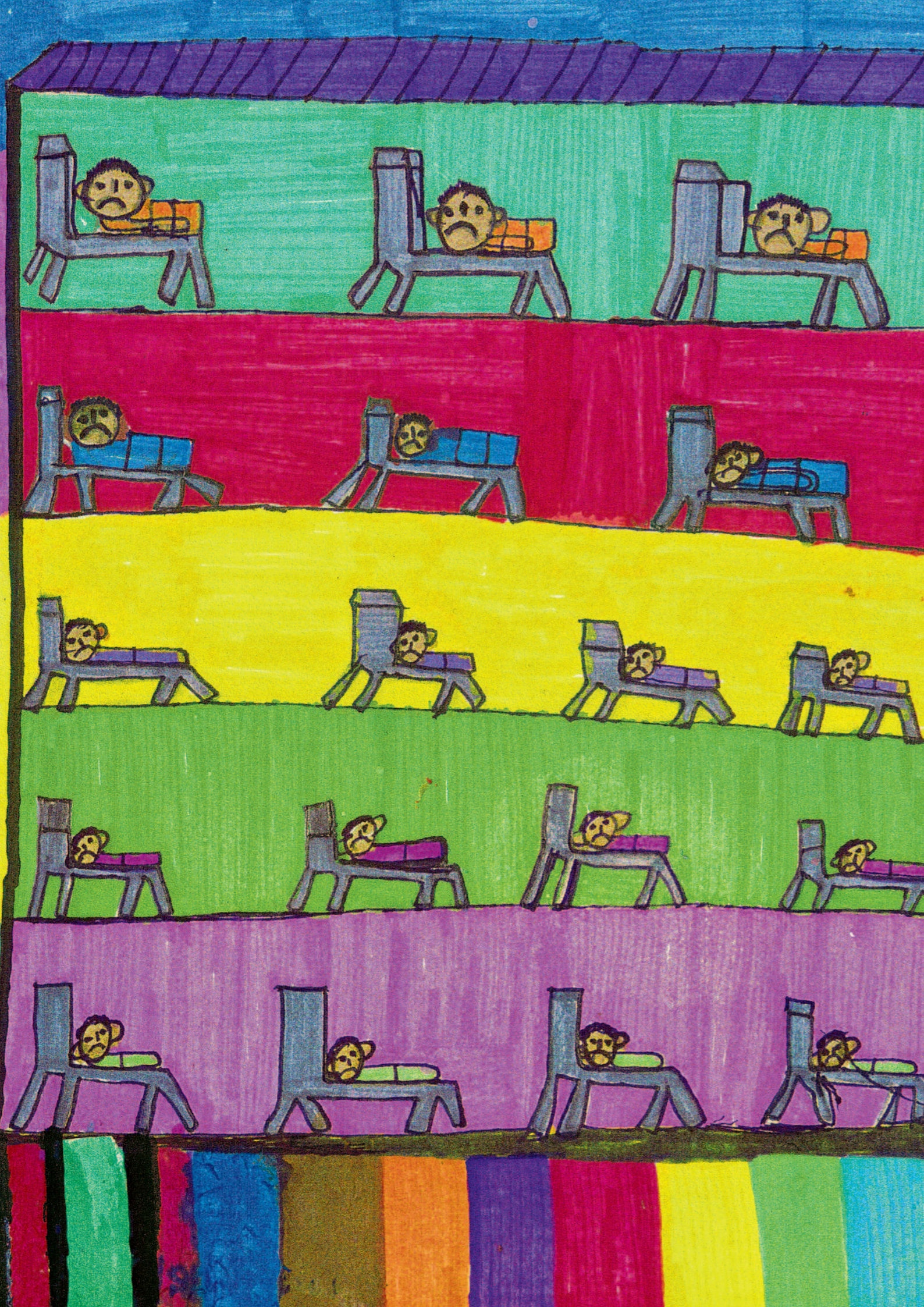
“Yes we can give kosher diets and things like that. I have had several kosher patients ask for a bacon sandwich! But the end of life plan is so different, for Jewish people you are not allowed to touch them when they die, you have to get the Rabbi in, you just lie them flat and you don’t do any messing about. Camchester hospice does some really good courses and I went on several a few years ago, a Bangladeshi awareness course, a Pakistani awareness course, West Indian, Chinese. And that gives you an insight into what their after life beliefs are so you can be empathetic and know what they want.” **Practitioner**

“We send people out to, well cultural awareness ... within that group as well, and again the local teams, the POPPS teams and the hospice team they do training sessions that we can send people to. We also have an end of life workbook ourselves.” **Manager**

Support for others after a death in the home

Working with people at the end of their lives inevitably means that issues around death and dying have an impact on a range of people around each individual. This includes family members, practitioners and other residents. All these people have feelings, fears, reactions and needs in terms of dealing with the death of someone they know, love and may well have been closely connected to for a long time. A holistic, personalised approach to end of life care for each individual must therefore include appropriate support for a range of people.

There are some you get closer to than others. It is strange when they are not around, you miss people, it is like you are at work a long time aren't you? **Practitioner**



Support for residents

Managers and practitioners spoke of a traditional reluctance in nursing and residential services to be open with residents when another resident dies.

However, they spoke of recent improvements:

“Yes it is something that we really tip-toe around, we do tip-toe around it a little bit, I know we do. I always feel a bit awkward when they (residents) do ask, I just do because I know how I feel at losing them so I know what it must feel for them.”

Practitioner

“Usually if one of them passes away we wouldn’t just say in the middle of them ‘so and so passed away’ because we don’t want to put them off or make them scared.” **Practitioner**

“You think it doesn’t affect them but it does. ... When somebody passes away because they do miss that person and again you have to talk to them about it. Because we have now started telling them, it is not something we used to do, but we have started telling them when somebody has passed away. It is like a member of their family and it is not fair. If someone is poorly we will say that person is not in the dining room because they are poorly today. They do take an interest actually.”

Manager

Managers and practitioners spoke of a traditional reluctance in nursing and residential services to be open with residents when another resident dies.

Previously, the issue was not confronted and took away the ability of residents to grieve the loss of someone who may have become a friend:

“They just disappeared and we had to have a rethink about it. Because the staff knew and really we should be telling the residents when somebody has passed away. What happened was they were always asking and the staff were fobbing them off and fobbing them off and I thought to myself at the end of the day they are mature adults. And yes they have a little cry and I think it does them good. We have actually had them go out to funerals as well, not recently but they have been out to funerals.” **Manager**

Support for practitioners

Many staff spoken with talked of their upset on the death of an older person they had been caring for:

“There are some you get closer to than others. It is strange when they are not around, you miss people, it is like you are at work a long time aren’t you?”

Practitioner

“Shocking sometimes, because I think some people pass away, some who seem ill will last and others they will just go. And it is sometimes a bit of a shock or a surprise should I say, not a shock. Obviously they are in nursing homes, this is their last place really.” **Practitioner**

A junior member of staff at a different home revealed that she could be deeply affected by the death of a resident:

“The way it makes people feel because some people get very upset. With me I get really upset so I don’t know about anybody else.”

Practitioner

Some practitioners spoke of not knowing how to behave on the death of an older person they had cared for, and were concerned about not knowing what a ‘professional’ response was:

“I am getting better at dealing with them (deaths), I used to cry, but that is not professional, I understand that, but it is hard when you have cared about them.”

Practitioner

Practitioners spoke about receiving regular supervision and support from their colleagues. However, we heard of very little formal support for practitioners following the death of a resident, most of it coming informally from colleagues and family members:

“Well there is a lot of peer group support because we work very closely within our teams. But having said that our manager and deputy manager are very aware of what is happening on the shop floor as well. So their door is never closed either. And again we have had fantastic support and given fantastic support from relatives and next of kin. Whether you like it or not you are more often part of an extended family living within an environment like this, it is very different to a hospital setting in that respect.” **Practitioner**

“Not as much as some people would like. I think there needs to be more out there. There is plenty out there for relatives but there is not much out there for staff.”

Practitioner

“Well we chat to other colleagues and support each other I suppose.” **Practitioner**

“[Name of deputy manager] and I have got a close working relationship so we tend to talk to each other. Or I talk to the qualified staff really, we do tend to support each other through that process. Residents become like a member of your family really and when you have had someone for five years you know end of life is the outcome but it still comes as a shock when it does happen.” **Manager**

A practitioner said that she did not receive formal support after a death. She felt that something like a support network might be helpful as some deaths could be quite upsetting. A manager at a different home recognised that staff usually found support among themselves but that a more focussed approach would be taken if someone, such as a new member of staff was having difficulties:

“I don’t particularly do a group basis discussion on it, but the team could talk, they may well talk amongst themselves, I know the care staff would talk amongst themselves. But if we knew someone was particularly struggling with it we do invite [Name of charity] in and one of the trained nurses. She is actually our palliative care nurse with the hospice, she is excellent, so we find her very supportive as well.”

Manager

Despite this lack of formal support, a manager spoke of the importance of support for staff following a death:

“And also the staff because if you have had someone who has been here for seven years and the member of staff has probably been looking after them for five, because some of the staff have been here that long, it is looking after the members of staff as well when that happens.” **Manager**

One member of staff described herself as ‘chief mourner’ at her care home and believed that she attended funerals ‘nine times out of ten’. This member of staff said that other members of staff went as well, ‘but it depends who is free, but I represent’.

Some staff in some care homes spoke of valuing professional help from the specialist team at the palliative care unit was revealed as being appreciated by some care home staff:

“ [name of hospice], they are palliative care nurses there but we also have a dedicated nurse from there that gives us help and support. We have a twenty-four hour help line here and that nurse who gives us the support also gives the residents support and their extended family support, it is a very broad support that they give us. And we only have to refer someone on and it doesn’t have to be cancer, it can be any end of life stage.” **Practitioner**

Practitioners are encouraged to attend the funerals of residents and express their grief if they wish:

“A lot of the staff go to the funerals as well and that is encouraged. And there is all this business about being po-faced and they shouldn’t cry, if you cry you cry, I haven’t got any major issues with that at all.” **Practitioner**

The role of hospice staff in providing support is revealed as additional to staff talking to each other in some situations:

“It is talking it through with them, seeing how they feel and preparing them. Because they are not stupid, they will come and say is this person going to make it, it is saying to them no you need to prepare yourself, that on this occasion they won’t get better. And we’ve had in the past counselling for staff from the hospice team. Because if someone has died suddenly that is the worst thing for the staff to deal with. Because they have may have been on duty the day before and that person is perfectly alright, they come on the next morning and they have died and it is a great shock. So we have had support from the hospice team for them, they have come in and done some counselling for us.” **Manager**

Suggestions for improving end of life care

The Project’s work in Camchester highlighted a range of issues and ideas that are important in making care and support at the end of life more human, personal and effective. This section brings together these suggestions, focusing particularly on three important issues: inter-disciplinary working; staff training; and decision-making.

We need to create a culture where staff, residents and families feel able to openly discuss their wishes and fears, make informed choices and get the end of life care they wish for. **Eve Richardson**

A staff nurse said that more time should be spent by practitioners to ensure end of life wishes are agreed clearly and recorded. This would have the effect of giving staff the confidence to resist pressures to admit residents to hospital and relieve any anxieties they may feel as a resident approaches the end of their life.

The role of GPs and interdisciplinary working

A staff nurse said that more time should be spent by practitioners to ensure end of life wishes are agreed clearly and recorded. This would have the effect of giving staff the confidence to resist pressures to admit residents to hospital and relieve any anxieties they may feel as a resident approaches the end of their life:

“Give everybody more time, the GPs to come out, a time when the GP can meet with the family and us altogether. Everybody seems to have very precious time. And you can understand it from the GPs point of view they look after many people, but to us that is important. What is important to one is not always important to another and while they want to give the best care it is actually the time factor. And as I said because of the legalities of everything, of having to have these forms signed and feel that is the most important thing, so we know we can say ‘no they are not going to hospital’ because everybody agrees, the resident, the family, the GP they all think it is in their best interest, that is the main thing.” **Practitioner**

One nurse felt that the system could be improved with residents having their end of life wishes explored with their GP as early as possible and endorsed prior to admission as well as after:

“I think the GPs, or when they see they are going down, they should at least make a plan with them. Then if it is forwarded to us it is already consented by their GP and their family, all we need to do is just confirm with their family and find also that that is what they want. Then things would be easier.” **Practitioner**

One nurse felt previous arrangements for out of hours care by GPs were better. When asked what would improve things she said:

“Having GPs doing 24 hour cover like they always did. We have a co-operative, so often we can have a GP who actually worked in a practice in Camchester coming to see a resident and he may be the resident’s particular doctor, although that is a bit of a coincidence. And that is much more helpful than a stranger coming in who would have to make a decision.” **Practitioner**

A manager outlined how a request from a resident to be allowed to die in the home and not be admitted to hospital should ideally be acted upon: “Talk to the GP and get the GP involved in it, because at the end of the day they are the ones who are making that final decision, it doesn’t rest with the nursing staff. Because we do get out of hours doctors who would come in and will try to get someone into hospital so we involve the GPs in that. And we may involve also the palliative care team from the hospice. Because it is not just about people who have got cancer, we may involve them in it as well. And there is again paperwork, there is an end of life pathway, there is paper work that the GP and the relatives or the resident actually sign that is then sent to the on call service to say, if you get a call about this resident you need to go and see them and not just automatically send an ambulance and send them to hospital, which is what some doctors would do.” **Manager**

One practitioner said that whether wishes are respected can be decided by the quality of relationships between the professionals involved: “(It) has got a lot to do with the health care professionals that are involved with that person.” **Practitioner**

Staff training

Training in dealing with end of life issues was generally valued but not all practitioners interviewed had received it. Also some practitioners said they felt that training in itself cannot prepare you for dealing with a real death:

“We have not had any recently, but we do have training from the hospice about all the end of life issues. It is covering things like basic care for the resident when they are reaching the end of life. We have even had the vicar here talking about spiritual and emotional support for staff and residents and relatives as well.” **Manager**

“Well it helps you because you kind of expect it, you kind of know what to do. But not really because you haven’t seen this thing before and no matter how much people tell you, you can’t just be prepared.” **Practitioner**

“In training you learn everything but when it comes to somebody dying it is something that you can’t really ... it is very hard, it is very difficult, I can’t put it into words.” **Practitioner**

“There is a unit (NVQ) you can do about dying and death and bereavement etc. Basically as you get used to the job you find your own techniques on how to deal with it. Basically it is not something you can do on paper, it is something you have got to gain with experience, maturity.” **Practitioner**

There was recognition in one home that it was early days in developing a smooth implementation of the policies required by the ‘Life Care Manual’: “As a company we have an end of life care manual which we have just implemented, and we are just trying to feed that back through the ranks really, so we are going to get that up and running.” **Manager**

The Mental Capacity Act 2005

The Mental Capacity Act of 2005 can be expected to have an influence on end of life choices in nursing and residential homes. Among other things, the Act sets out the jurisdiction of a new Court of Protection to make declarations and orders and to appoint substitute decision-makers or ‘deputies’, where a person lacks capacity:

“With the Mental Capacity Act coming into force that is going to throw up problems. Because what they are saying is it should be the resident who is making that decision for themselves. But if somebody has got dementia when they are admitted how do you actually do that? They haven’t given us a solution to that.”

Manager

“The Act is only just coming into being so I think any decisions made before it came in to force will still stand. But the problems will arise for managers from now on. We in the past have asked relatives do you want your loved ones going into hospital or do you want them to be nursed here? And the vast majority want them to be nursed here. But what the Mental Capacity Act is saying is that is not legal.”

Manager

A manager indicated that there were plans to begin to get to grips with this legislation:

“We have been given an opportunity, I have not got the dates yet, from Camchester to go on little, not too much information but guidelines on how to deal with the Mental Capacity Act. That is the sort of advice, it narrows it down here for our staff because you can’t blind them with information but at the end of the day if somebody says ‘no’ they say ‘no’.”

Manager

Booklet for relatives

A manager outlined a problem faced by relatives following the death of a resident:

“We still get relatives coming back (saying) ‘Yes they have died but what do we do now?’ There was a booklet produced which was very, very good but then it just disappeared because we asked for additional copies. Because what we used to do is give it to relatives and say ‘Right this is what you need to do’, it goes through everything and then it disappeared. It came out from the government and then it just disappeared off the market.”

Manager

The manager said it would be useful to have a similar booklet to give out:

“It is going through it with them but what we have got to appreciate is they don’t retain that because it is a stressful time for them. Somebody has just died they have got to have the grieving time and everything and something written down would be very, very useful for them. And they can go through it and say ‘Right I have got to do this, I need to do that, and this is who I need to contact, this is who I need to send the death certificates to and this is how many copies I need’.”

Manager

Conclusions

The following general findings emerged from the research:

- There are differences between homes, on a number of the issues explored in the research. For example, in one care home in particular an interviewee expressed a lack of confidence in how the system for end of life planning worked there. The same lack of confidence was not portrayed by others to the same degree and did not emerge elsewhere. This may demonstrate a possible difference between this home and others. In other homes there were differences in the experience of interdisciplinary working with GP’s.
- Most residents, with one exception, seemed content with the service they receive (and how person centred it is). They felt they were free to take many decisions for themselves; people specifically mentioned being able to personalise their rooms to some degree for example.
- The concept of person centred care is not a familiar term to relatives and carers. One, however, outlined how her late mother had experienced the freedom to plan the end of her life including stating a wish to have no further treatment and the form of her funeral.
- Staff said they were doing their best in trying to approach care in a person centred way. This included end of life plans using the policies and protocols available, of which all staff interviewed were aware.

The following conclusions relate to the individual sections of this report:

Planning person-centred care

1. With one exception all the residents we spoke to said they were happy with the care they were receiving.
2. Many older people simply said they had not thought about choices at the end of their lives.
3. Some residents did not wish to discuss the matter.
4. Only a minority of the residents we spoke to said they had spoken about end of life care with staff.
5. Some older people we spoke to had spoken to their relatives about choices at the end of their lives.
6. None of the residents we spoke to said they had spoken to their GP about end of life care.
7. We found that many relatives were making important decisions on behalf of their loved one. Two residents said they were happy for their relatives to make these decisions on their behalf.
8. Several residents had thought about and made decisions about their funeral. This was one area about the end of their lives that the majority of residents had made decisions about.
9. Only one resident had recorded decisions about their end of life in writing. None had advanced care directives.

Barriers to person-centred care

1. We found there was a widespread reluctance among practitioners to talk about end of life choices with residents. This was particularly true among junior staff and care assistants. However staff understood the importance of discussing the issue and all homes had paperwork covering the subject that is supposed to be filled in by staff when residents move in.
2. A key barrier to recording end of life decisions was finding an appropriate time to discuss them. Many staff said that it was difficult or inappropriate to have these discussions before they built a relationship with a resident.
3. The impact of the end of life on relatives was noted. Many staff said they saw part of their role as supporting relatives. One group of relatives at a local nursing home have formed their own support group.
4. Practitioners expressed concerns that in the past relatives have made decisions on behalf of residents. Although many spoke of changes there was evidence of this still happening in relation to important end of life decisions, for example relatives signing a 'do not resuscitate' form for their mother without speaking to her about it or knowing that staff had spoken to her.
5. One resident criticised staff attitudes, saying they like to boss old people around.
6. Some interviewees referred to insufficient staffing to provide what they saw as good practice care for people in end of life care. This was attributed to funding constraints.
7. There was consensus that best practice was to avoid the use of agency staff for people in end of life care. The reason is continuity of care. The majority of homes in our study rely instead on bank staff.

8. Staff spoke of the need for end of life paperwork to be signed by all necessary parties, including GPs. Without these signatures there could be problems of people being admitted to hospital against previously expressed wishes not to be admitted to hospital. Out of hours arrangements were criticised as was the complicated situation relating to whether a 'DNAR' from hospital applied in other circumstances.
9. Several examples were given of residents choosing to die at their care home, which had happened in line with the residents choice. Relatives were not seen as a significant barrier to this. However some traumatic incidents were described, including one where a resident was resuscitated in front of her family as a DNAR form supplied for an earlier ambulance journey from hospital was no longer valid.
10. Some practitioners thought that some referrals to their home were hasty or inappropriate. They attributed this to hospitals and Adult Services wanting to reduce 'bed blocking'. This could, for example lead to people being transferred to a home when they are too ill, or to a home a long distance from relatives.
11. Some practitioners spoke of fears of being criticised for not making attempts to resuscitate residents, even if this is against their stated wishes.
12. Cultural differences within care homes were explored. The virtual total absence of residents from ethnic minority groups was revealed in relation to all the homes that were part of this study. In one home all the residents were white and nearly all the staff were from African countries. Some problems that had occurred in the past were now felt to be resolved favourably with a good interaction between residents and staff.

Support for others after a death in the home

1. Practitioners described a traditional reluctance in nursing and residential homes to tell residents about the death of their fellow residents. They spoke of improvements in this area but their comments reveal an ongoing reluctance to approach the subject openly.
2. Some practitioners' contributions revealed a lack of organised support for staff who may be distressed at the death of residents. Practitioners receive regular supervision and currently deal with their feelings by talking to and supporting each other.

Suggestions for improving end of life care

1. Practitioners said that GPs should explore end of life choices with residents and nursing and residential homes. They said that the quality of relationships between professionals was important in enabling person centred support. Overall they said more time was needed by all professionals involved in supporting end of life decision making.
2. Practitioners valued training in end of life choices, however many said that training in itself cannot prepare you for dealing with a real death.
3. The Mental Capacity Act (2005) has implications for nursing and residential homes in relation to decision making by residents.
4. A manager of a nursing home said it was useful to have a booklet of practical information for relatives about what to do when their loved one dies.

Recommendations

Individual choices

1. Residents of residential and nursing homes should, whenever they have capacity, make decisions for themselves. They should be supported by practitioners and relatives when this is necessary. Homes should ensure that their policies and procedures fully reflect the principle and requirements of the Mental Capacity Act (2005).
2. Residents who are adjudged not to have capacity to make a particular decision and no next of kin have access to advocacy via the Independent Mental Capacity Advocate (IMCA) scheme. However many service users who have capacity do not have relatives or friends to help with making decisions but would not qualify for advocacy via the IMCA scheme. Residential and nursing homes should build links with local advocacy organisations and support residents to access advocacy.

General

3. There should be a more general openness about the subject of death for all people. Efforts should be made to promote an earlier consideration of end of life choices amongst the general public. It would be valuable for people to consider these issues prior to becoming ill. This could be done via schools, hospitals, GP surgeries, libraries and local voluntary organisations.
4. Many service users admitted to residential and nursing homes from hospital have previously been given information and answered questions about cardiopulmonary resuscitation and choices approaching the end of life. The transfer of this information to the home would be a useful interim measure, filling the gap between arrival and further conversations about end of life choices. It would avoid the need for the repetition of sensitive questions on admission to the home.
5. Residents in nursing and residential homes benefit from time to consider their options relating to end of life decisions. Therefore it is important that those practitioners, relatives and GPs involved are able to take the necessary time to support informed and considered decision making.

Nursing and residential homes

6. There should be more openness about dying and death within care homes; this would enable residents, relatives and practitioners to talk honestly about end of life choices at an earlier point. Residents should have the right to know when residents they are friendly with die. These measures could help foster an atmosphere where residents can offer each other emotional support. Good examples of this include homes hosting funeral teas for deceased residents' family and friends.
7. Residential and nursing homes are required to have a policy about end of life care. National standards and guidance exist but individual companies or organisations develop their own policies. Residents and their relatives could play an important role in the process of developing end of life care policies.
8. There were very few residents from black and minority ethnic groups living at the nursing and residential homes that were part of our study. Further research may be of benefit in examining cultural awareness in nursing and residential homes and to look into the apparently low number of people from black and minority ethnic groups moving to a home.

Training

9. There is evidently a need for regular staff training around choices in end of life care. We understand this training is available locally and would encourage managers and practitioners from all nursing and residential homes to attend. This training could potentially call on the expertise of voluntary or charitable organisations with expertise in bereavement and user involvement in services.
10. If nursing homes are expected to take on residents with more complex palliative care needs their staff would benefit from access to the training available to PCT staff through the Regional Collaborative.

11. Commissioners could consider minimum standards for elements of end of life care choices as part of the commissioning process. For example specifying training requirements relating to choices in end of life care in Service Level Agreements.

Relatives and carers

12. Support groups for relatives and carers of residents have been established in several homes in Camchester. The groups can play an important role in providing mutual support information about end of life care promoting open dialogue with professionals. They should be supported by homes but run and governed by residents/relatives.
13. A booklet for relatives and carers providing information about options towards the end of life, and what to do when their loved one dies would clearly be useful. Building on the existing work of a number of homes this resource should be developed so that every home can hand it out as and when needed.

Resuscitation

14. It is essential that the necessary, signed paperwork is available for people who have specified a wish not to be resuscitated or for whom resuscitation is not clinically indicated. Deficiencies in this paperwork can lead to distressing and traumatic incidents at the end of life.
15. (See Appendix 2) The potential for an extended role of nurses in making judgements about treatment at the end of life could help ensure service users' decisions are respected. However it is dependent on agreements made at a local level so development of local policy is crucial in taking advantage of its potential thus avoiding increased bureaucracy or unwanted responsibilities for practitioners.

GPs

16. GPs should discuss choices in end of life care with their patients who live in nursing and residential homes. The involvement of a GP could help clarify decisions and support nursing and residential home practitioners in recording and respecting individual residents' decisions.
17. The study found that the quality of relationships between nursing and residential homes and GPs vary. Some problems arise from homes having to link with a number of different GP practices. If residents from each home were given the option of joining the list of a single GP practice (with established links to that home), improvements could be made in continuity of care. A regular weekly GP visit to each home would help build relationships and the confidence of residents. The GP could also sign nursing records regularly; this would mean that fewer residents die without seeing a GP in the preceding 2 weeks.
18. Efforts should be made to improve the quality of relationships between nursing/residential homes and 'out of hours' GP services.

Appendices

Appendix 1: People involved in the research

The Chief Investigator: Jennie Fleming, Centre for Social Action, De Montfort University funded by Joseph Rowntree Foundation.

Researchers: Jennie Fleming, Michael Glynn and Rod Griffin.

The Steering Group in Camchester:

- Associate Director Modernisation of Older People's Services, Camchester PCT
- User/Carer Representative
- Community Specialist Palliative Care, [Name] Hospice, Camchester
- Matron, [Name] Hospital, Camchester, Camchester Teaching Hospitals Foundation Trust
- Commissioning Advisor, Neighbourhoods & Community Care, Camchester City Council
- Acting Head of Older People's Services, Camchester PCT
- Team Manager, POPPs Support Care Homes, Camchester PCT
- Palliative Care Team, Camchester Teaching Hospitals NHS Foundation Trust
- Specialist Nurse Older People, POPPS Team, Camchester PCT
- Consultant Community Geriatrician, Camchester Teaching Hospitals Foundation Trust

Appendix 2: An extended role for nurses

A national policy development that could ultimately have implications for end of life care in nursing and residential homes involves an extended role for senior nurses. The policy was formally announced towards the end of the fieldwork of this project. It is felt to have relevance in exploring the future of these issues.

In October 2007 guidelines were published, framed in agreement between the British Medical Association (BMA), The Royal College of Nursing (RCN) and The Resuscitation Council stating that not only doctors but also suitably experienced nurses will be able to make a judgement about whether a patient whose heart or lungs have stopped should be resuscitated. This is the first time that senior nurses have been given a power in which they can make a judgement, without the authority of a doctor if they think that life saving techniques will be unsuccessful. Under these guidelines, it is required that each patient should be assessed and healthcare professionals notified of decisions taken.

The following requirements are outlined in the guidelines:

- All establishments that face decisions about attempting CPR, including hospitals, general practices, residential care homes and ambulance services, should have in place a policy about resuscitation attempts.
- Health professionals are aware that decisions about attempting resuscitation raise very sensitive and potentially distressing issues for the patient and people emotionally close to the patient.

- Local policy makers may find it helpful, however, to tailor policies to their own particular setting, to ensure they are relevant to the type of patients being cared for and take account of what facilities are available.
 - It is also essential to identify those patients who do not want CPR to be attempted and who competently refuse it.
- 'Decisions relating to cardiopulmonary resuscitation' (2007) Joint publication by the BMA, RCN and the Resuscitation Council. Available to download at:
www.bma.org.uk/ethics/cardiopulmonary_resuscitation

It is also stated in the guidance, however, that it is not always appropriate to discuss this issue with an individual who may be dying and could be distressed.

It has been pointed out that nurses who authorise such decisions may still have to justify their actions in court or at an inquest. The seniority of appropriate nurses has been considered by the RCN to be at matron or nurse consultant level.

It has been stated that this guidance applies not just to hospitals but aboard ambulances and in palliative care. This new guidance will not change the situation of most nurses working in nursing and residential homes for older people but will add other, senior, nurse members to the team (including perhaps from Palliative Care) who could assist in endorsing end of life decisions and making sure they are supported.

Useful organisations

Government departments

Department of Constitutional Affairs
Mental Capacity Implementation Team
5th Floor
Steel House
11 Tothill Street
London SW1H 9LH
Telephone: 020 7210 0037
Email: makingdecisions@dca.gsi.gov.uk
www.dca.gov.uk

Department of Health
This website includes a list of all local Independent Mental Capacity Advocate (IMCA) services. For more information about what an IMCA is and a list of all IMCA services across the country, contact:
www.dh.gov.uk/mca

Equality commissions

The Equality and Human Rights Commission
Equality and Human Rights Commission (England)
Freepost RRLR-GHUX-CTR
Arndale House
Arndale Centre
Manchester M4 3EQ
Telephone: 0845 604 6610
Textphone: 0845 604 6620
Fax: 0845 604 6630
www.equalityhumanrights.com

Equality and Human Rights Commission (Wales)
Freepost RRLR-UEYB-UYZL
1st Floor, 3 Callaghan Square
Cardiff CF10 5BT
Telephone: 0845 604 8810
Textphone: 0845 604 8820

Equality and Human Rights Commission (Scotland)
Freepost RRLR-GYLB-UJTA
The Optima Building
58 Robertson Street
Glasgow G2 8DU
Telephone: 0845 604 5510
Textphone: 0845 604 5520

National service user and disabled people's organisations

Shaping Our Lives
National User Network
BM Box 4845
London WC1N 3XX
Telephone: 0845 241 0383
www.shapingourlives.org.uk

SOLNET website of organisations of people
www.solnetwork.org.uk

National Centre for Independent Living
Unit 3.40
Canterbury Court
1-3 Brixton Road
London SW9 6DE
Telephone: 020 7587 1663
Advice Line: 0845 026 4748

Self advocacy
To find your local self advocacy group you can go to the website of the National Forum:
www.nationalforum.co.uk

People First
A self advocacy organisation run by people with learning difficulties based in London is:
www.people-first.co.uk

Other national organisations

Action for Advocacy
PO Box 31856
Lorimore Square
London SE17 3XR
Telephone: 020 7820 7868
www.actionforadvocacy.org.uk

Housing Options
Stanelaw House
Sutton Lane
Witney
Oxfordshire OX29 5RY
Telephone: (0845) 456 1497
www.housingoptions.org.uk

National Association of Citizen Advice Bureaux
www.nacab.org.uk
www.adviceguide.org.uk

National Association for Voluntary and Community Action
The Tower
2 Furnival Square
Sheffield S1 4QL
Telephone: 0114 278 6636
Textphone: 0114 278 7025
www.navca.org.uk

National Brokerage Network
3 The Courtyard
Windhill
Bishops Stortford
Herts CM23 2ND
Telephone: 01279 504735
www.nationalbrokeragenetwork.org.uk

Social Care Institute for Excellence
Goldings House
2 Hay's Lane
London SE1 2HB
Telephone: 020 7089 6840
Textphone: 020 7089 6893
www.scie.org.uk

Values Into Action
PO Box 59043
London E13 3AZ
Telephone: 07754 157718
www.viauk.org

Reports from the Project

The Standards We Expect Project has produced a range of documents about person-centred support written for a variety of people on a variety of topics.

You can find out how to get a hard copy or download a copy from these websites:

www.shapingourlives.org.uk
www.policypress.co.uk

The website will also tell you how to get Word copies of the documents which can be downloaded for use with computer readers or in large font versions.

Supporting People: towards a person-centred approach

Peter Beresford, Jennie Fleming, Michael Glynn, Catherine Bewley, Fran Branfield, Suzy Croft, Karen Postle

Published by Policy Press 2011

Supporting People: towards a person-centred approach Findings

Peter Beresford, Jennie Fleming, Michael Glynn, Catherine Bewley, Fran Branfield, Suzy Croft, Karen Postle

Published by Joseph Rowntree Foundation 2011

Supporting People: the big issues

Peter Beresford, Jennie Fleming, Michael Glynn, Catherine Bewley, Fran Branfield, Suzy Croft, Karen Postle

Published by Joseph Rowntree Foundation 2011

Supporting People: a summary in easy words and pictures

Gina Barrett, Maggie Brennan, Dana Brown, Neil Burton, Wenda Gordons and Christina Watkins from People First Lambeth with Hom Saihkay and Catherine Bewley

Person-Centred Support: a guide for service users

Catherine Bewley, Fran Branfield, Michael Glynn, Peter Beresford, Suzy Croft, Jennie Fleming, Karen Postle

Person-Centred Support: a guide to person-centred working for practitioners

Suzy Croft, Catherine Bewley, Peter Beresford, Fran Branfield, Jennie Fleming, Michael Glynn, Karen Postle

Making a Change: a guide to running successful and accessible workshops and training

Michael Glynn, Fran Branfield, Catherine Bewley, Suzy Croft, Jennie Fleming, Karen Postle

Person-Centred Support: choices for end of life care

Jennie Fleming, Michael Glynn, Rod Griffin, Peter Beresford, Catherine Bewley, Fran Branfield, Suzy Croft, Karen Postle

Working towards Person-Centred Support: a local case study

Karen Postle, Suzy Croft, Jennie Fleming, Peter Beresford, Catherine Bewley, Fran Branfield, Michael Glynn

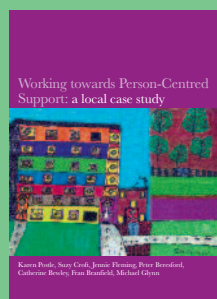
THE STANDARDS WE EXPECT...



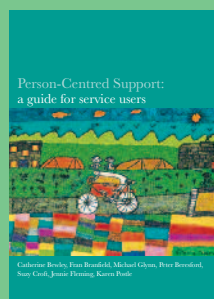
Front cover illustration 'The long stay ward and the side room' © Kevin Chettle and with permission from Advocacy in Action

This report is one of a series linked with the national Standards We Expect Project supported by the Joseph Rowntree Foundation. The purpose of this national project was to develop person-centred support in social care and other services, in line with the 'standards' that service users wanted. It focused particularly on including the views and experience of people as service users, informal carers and face-to-face practitioners. The aim was to find out what barriers were getting in the way of disabled people and service users having the services and support they wanted and how these barriers could be overcome.

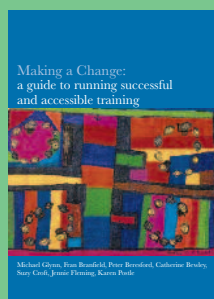
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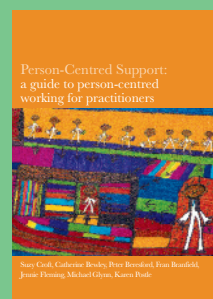
Working towards Person-Centred Support: a local case study



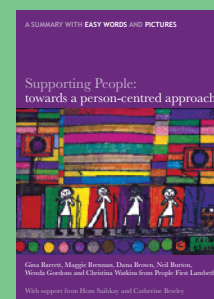
Person-Centred Support: a guide for service users



Making a Change: a guide to running successful and accessible training



Person-Centred Support: a guide to person-centred working for practitioners



Supporting People: towards a person-centred approach