

What is important to residents with neurological conditions and their relatives in rehabilitation and long-term care centres?



Cover design - the cover is a Photoshop montage based on the pictures of 'good care' and 'bad care' drawn by research participants.

What is important to residents with neurological conditions and their relatives in rehabilitation and long-term care centres?

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Dedication:

To: All staff, residents and relatives, past and present from Julie – this is for you, in acknowledgement of the challenges we faced together.

To: To Polly from Jenny – this is for you - sister, friend, adventurer, advocate - in honour of your passionate commitment to service user involvement.

Acknowledgements:

With thanks to Cardiff University, for their contribution towards the time of Professor Jenny Kitzinger; and to Ramsay Health Care UK for funding the time of Julie Latchem.

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Executive Research Summary

‘What is important to residents with neurological conditions and their relatives in rehabilitation and long-term care centres?’

Julie Latchem and Jenny Kitzienger

The Research:

This research examined residents’ and relatives’ perspectives on what is important in rehabilitation and long-term care centres for people with neurological conditions.

- The research participants were residents at three UK neurological centres and relatives with loved ones at these centres. In total 14 residents and 19 relatives participated in the research.
- Data was collected via focus groups and interviews.
- The residents who participated in the research all had the mental capacity to consent to the research on their own behalf; the relatives who participated mainly had loved ones with more profound mental and physical impairments.

Key Findings:

1. One of the strongest themes that emerged from the research was the importance both residents and relatives placed on the quality of residents’ relationships with staff. Participants talked emphatically, and at length, about the importance of staff friendliness, respect, and professionalism alongside highlighting how they wanted staff to care, not only physically but *emotionally*. Residents also expressed their need to be known by staff personally, as an individual. Residents also emphasised the value of their relationships with *one another*, and much camaraderie and care between residents came across in the data.

2. Residents and relatives placed emphasis on the importance of various aspects of physical care, including good basic medical and nursing care and having physical needs met in a timely way. They repeatedly highlighted the importance of therapeutic input and residents, in particular, highlighted the value of physiotherapy.

Residents specifically discussed the importance of touch - not only stressing the importance of the way they are physically handled by staff but also articulating their need for affectionate touch and the role it plays in their day to day lives – helping them to feel ‘human’ and ‘connected’.

3. Residents and relatives identified the need for residents to remain connected to their social circles, the local community and the wider world wherever possible and relatives considered their role in facilitating this. Residents and relatives also highlighted the value of being provided with information directly relating to the care environment and stressed the importance of residents being able to use the internet, keep up with the latest news and the facilitation of independent communication.

4. Residents and relatives emphasised the importance of residents having as much choice, control and independence as possible in relation to physical tasks, day-to-day activities and decision-making.

5. Research participants highlighted the need for stimulation and meaningful activity, e.g. through trips out, everyday in-house activities, organised events and socialising.

6. The general environment was identified as an important aspect of long-term care settings. Space, noise, equipment, facilities (e.g. access to hot drinks, seating), services (e.g. laundry, catering) and equipment were all deemed important. Research participants also highlighted the significance of security (e.g. in relation to physical safety, the security of possessions, and access in and out of the care environment).

7. Both residents and relatives considered a friendly and positive atmosphere as crucial and relatives in particular emphasised the importance of ‘homeliness’ and sense of community.

8. Some additional issues raised by relatives included: concerns about the financial security of the residents' placement and care (e.g. funding issues).

9. Relatives also emphasised their need for regular and accurate medical information and the importance of good communication from health care professionals, and discussed their desire to input into medical decision-making to support their loved one.

10. Like residents, relatives also consider their *own* relationships with staff as very important. They discussed this alongside the wider context of their role in the care team as a whole. Relatives valued being known by staff, feeling welcomed and a part of the centre’s community. They appreciated staff who recognised the role they had to play in caring for their loved one and who were willing to work *with* them to determine how best to support residents.

11. Finally, focus group discussion also captured a series of key tensions that both residents and relatives experience. These included conflicts regarding independence versus security, routine versus institutionalisation and individual versus collective needs.

We will be presenting this report to service users, service providers, and service funders, evaluators and policy makers – and hope that this will help to support the crucial trend towards putting service user perspectives central to services.

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Setting the Scene: The Importance of Service Users' Views

1.1 The importance of service users' views

Long-term care immediately conjures up the image of elderly care homes; however, many younger people with complex conditions require care in an environment that is neither hospital nor home. With medical advances many more people are living for longer with more severe disabilities. Caring for these individuals presents not only a medical challenge but also a social one. Much work has looked at care of the elderly in residential and nursing homes (Cooney et al., 2009; Dickson et al., 2008; Kapp, 2003, Robichaud et al., 2006) and some has examined brain injured individuals living at home or 'in the community' (Winkler et al., 2010; Geurtsen et al., 2007; Chard et al., 2011). Such research does not, however, include the young individual with a neurological condition requiring long-term care in an institution.

Throughout healthcare, quality indicators are crucial for ensuring clinical quality and service improvement. Key data collated to assess quality of care include: 1) Clinical Governance audits (i.e. medical records, medicine management, infection control) used to monitor quality and benchmark across a particular service. 2) monitoring of patient outcome through clinical outcome measures such as the Northwick Park Dependency Score and various other therapeutic based scores such as the BERG Balance score, FIM/FAM etc. 3) patient and stakeholder feedback. This is often collated from satisfaction surveys, meetings and forums.

Despite the efforts made to collate patient feedback this is often done with the mind set of service review. Service review is a required and useful approach; it does not, however, inform providers about what is important to their patients, as Powell et al. commented back in 1994 '*...other views of quality need to be included within the specification of standards. Standards of practice are crucial to the users of services, but users are rarely involved in the process of establishing them.*' (Powell et al., 1994, p199)

In 2001, a similar sentiment was mirrored by van Wersch and Eccles who report that despite service user involvement being advocated, they found few examples and evidence demonstrating this in practice. However, despite the slow uptake there have been some significant advances made over the past five years. *'Involving patients in service improvement and listening and responding to what they say has played a key part in the redesign of healthcare processes over the past five years and more. Patients and users have attended stakeholder events, participated in discovery interviews, completed surveys, mapped healthcare processes and even designed new hospitals with healthcare staff.'* (Bate and Robert, 2006, p307)

These developments, however, did not come without criticism. *'If we truly wish the public to engage in decisions about health and social care we need to distinguish between initiatives that provide opportunities for meaningful input and action and those that amount to little more than an 'empty ritual.'* (Craig, 2008, p286.)

Service user involvement within health care has had a history full of debate and a lengthy and on-going process of engagement. *'Modern health care is recognising, albeit with difficulty, that it is a service industry and has to pay more attention to those who use it.'* (Elwyn et al., 2007, p1021) However, following legislation such as the new Care Quality Commission *'Essential standards of quality and safety, 2010'*, service user involvement is no longer simply a philosophical ideal but is an imbedded expectation within health care frameworks and legislation. Engaging service users and seeking their experience is now obligatory in all areas of health care.

There is, however, a distinct difference between involving service users in reviewing the service they receive and attempting to start from their priorities and establish what is important to them. As Bate and Robert (2006) point out: *'...to date efforts have not necessarily focused on the patient's experience, beyond asking what was good and what was not. Questions were not asked to find out details of what the experience was or should be like ('experience' being different from 'attitudes') and the information then systematically used to co-design services with patients. Knowledge of the experience, held only by the patient, is unique and precious.'* (Bate and Robert, 2006, p307)

This research aims to find out what is important to residents and their relatives rather than asking them to rate the current service. We hope that gaining a more in-depth understanding of what is important to residents and their relatives will help to improve services informed by genuine service-user involvement.

1.2 Development of the research collaboration

This research developed out of a collaboration between Julie Latchem, MCSP and Professor Jenny Kitzynger. The project's chief Investigator Julie Latchem (Matron at The Dean Neurological Centre 2010-11) has 6 years of clinical experience as a practising physiotherapist in the NHS and independent sector. Her clinical background is in neurology and rehabilitation. Her Matron's role within the independent sector provided exposure to legislation, practical application of CQC outcomes, engagement with commissioners and on-going service review and improvement.

Jenny Kitzynger is professor of communications research at Cardiff University and has written about a wide range of health issues including AIDS, cancer and residential care for the elderly, as well as conducting research around ethics and risk in health fields such as human genetics and brain injury. Jenny also has a severely brain injured sister living in a long-term residential setting – a sister who, prior to her car accident, was a mental health advocate and service-user involvement officer.

Such collaboration provides contrasting and complementing perspectives, bringing into dialogue the experience of clinician - relative, Allied Health Professional – academic. Both parties contribute levels of practical experience, clinical and research expertise crucial to the design and conducting of the research, creating a fusion between health practice and social science.

Methodology

2.1 Method selection

In order to investigate what was important to residents and relatives, a qualitative multi-methods design was employed. Qualitative research aims to develop *'...concepts which help us to understand social phenomena in natural (rather than experimental) settings, giving due emphasis to the meanings, experiences, and views of all the participants.'* (Pope and Mays 1995). Qualitative research is *'...concerned with answering questions such as "What is X and how does X vary in different circumstances, and why?" rather than "How many X's are there?"* (Pope and Mays, 1996, p3).

Why employ a qualitative approach?

In essence, this research study required complete focus on the opinions, interactions, attitudes and perceptions of the study population in order to answer the research question. *'...because health care deals with people and people are, on the whole, more complex than the subjects of the natural sciences, there is a whole set of questions about human interaction and how people interpret interaction to which health professionals may need answers [...] Experimental and quantitative methods are less well suited to answer these questions.'* (Pope and Mays, 1996, p5).

Two main methods were selected, focus groups and semi-structured interviews, both of which were audio recorded and then transcribed for analysis.

What is a focus group and why use them?

Focus groups are a form of group discussion or group interview. The groups have 'focus' due to the undertaking of some form of shared task, i.e. discussing a specific set of questions and are particularly useful for exploring people's knowledge and experiences. A crucial element provided by such groups is that focus groups capitalize on communication between research participants in order to generate data (Kitzienger 1995).

Focus groups are also *'...particularly useful for allowing participants to generate their own questions, frame concepts and to pursue their own priorities, on their own terms, in their own vocabulary'* (Kitzienger, 1999, p5). Such a methodology was therefore not only practically suited to the research question but also captures the principles of service-user involvement underpinning the research.

Designing the focus group session and devising prompts

Through the research team's knowledge of the research participants and methodological experience, a plan detailing how each focus group and interview would be conducted was produced (See Question Design, appendix A). It was recognized that some groups may require 'prompts' and have difficulty in discussing potentially emotive topics in depth from the outset. Two forms of prompt that could be added to focus group sessions and interviews were therefore devised: the first consisted of asking participants to rate a set of pre-written cards, the second asking participants to draw pictures of 'good care' and 'bad care'. These prompts were introduced as required.

The invitation to draw pictures proved to be particularly revealing. While some research participants were too self-conscious to draw (and some residents were unable to due to physical impairment), the drawings that were contributed are very eloquent (and suggest the need for exploring other creative data collection techniques too). Appendix B shows examples of the type of images research participants produced. It was striking that the images of 'bad care' showed figures alone, isolated or ignored. 'Good care' images produced by diverse relatives and residents represented the resident as at the centre of a network of care, affection and team work, as well as drawing out specific points such as the value of touch, or the importance of good communication about medical care. We use examples of pictures drawn by research participants throughout this report to illustrate key themes.

Maximizing participation by also having the option of interviews

Focus groups, although our method of choice and suitable for some participants, would be difficult for others. This is due to the likely length of focus groups, the requirement for concentration and the ability of participants to cope in a group situation. Focus groups are also notoriously difficult to organize, because of the practicalities of getting all participants in a group in the same place at the same time (and this is still true even in a residential setting due to residents' care needs). The decision was taken to also carry out semi-structured interviews with any participants who would not be able to manage in a focus group situation or were unable to attend organized focus groups.

What are semi-structured interviews and why use them?

'Semi-structured interviews are conducted on the basis of a loose structure consisting of open-ended questions that define the area to be explored, at least initially, and from which the interviewer or interviewee may divulge to pursue an idea or response in more detail.' (Britten, 1999, p.13). Semi-structured interviews were chosen to allow participants to share their views, thoughts and feelings but retaining some focus to ensure that data collection was relevant to the research question. This approach would also allow the interviewer to utilize a grounded theory approach during the development of the study and with each subsequent set of data collation, probing in more depth areas that emerged as requiring further investigation.

Why not use other methods?

Care services routinely undertake a series of resident/relative/staff meetings and surveys in an effort to evaluate the service. These approaches, however, have not led to the gathering of information in order to answer the research question and have a variety of limitations. Generalized meetings can be unproductive and disappointing with regards to data generation. Conversely, more formally planned meetings with 'focus' and an understanding from all that the purpose of the meeting is to gain information to lead to service improvement have been anecdotally beneficial.

As highlighted by Gibbs (1997), focus groups, however, offer much more than a productive meeting; they provide the potential for gathering data; attitudes, feelings and beliefs that although they may exist independently are only aired through group interaction and would not have been accessed via other methods such as observation, one-to-one interviewing or questionnaires.

Residents can require assistance to complete surveys and questionnaires and this can significantly compromise confidentiality and affect validity. Surveys and questionnaires in themselves have limitations due to the need for pre-set categories and closed questions and are often seen as more appropriate for discovering how many people 'hold' a certain (predefined) 'opinion' rather than exploring people's points of view on their own terms. These examples further support the methodological choice of focus groups and semi-structured interviews.

2.2 Ethics and refinement of the project design

Informed consent is required for participation within research studies and involving those without capacity immediately stimulates significant ethical debate. Initial discussion was held between the researchers to consider any potential harm that could be caused to those without capacity participating in the study and, in some cases, the limitations of being able to participate (e.g. some residents are in a vegetative or minimally conscious state, or have other profound neurological impairments). Although no likely damage or distress could be identified, it was considered that those lacking capacity would require significant support and many already have designated advocates that could provide this support in part.

Many relatives already act as advocates for residents within long-term care settings. We were interested, therefore, in involving relatives as co-researchers, to assist and facilitate the involvement of residents without capacity.

Further ethical considerations included the physical and cognitive tolerance of residents to participate and their ability to communicate. In order to safeguard these individuals, inclusion/exclusion criteria were established (see sampling criteria) and to reduce bias and aid residents to feel comfortable to participate, the research design insured that data was always collected by members of the research team who were not involved in the treatment of any of the residents they interviewed.

The research study proposal was presented to the relevant committee from the care organization. Following approval from the committee, ethical approval for the study was sought from the Social Care Research Ethics Committee. The Social Care Research Ethics Committee, however, raised concerns regarding our wish to involve relatives as co-researchers, seeming to feel this verged on using relatives as proxies, speaking on behalf of residents without capacity *'The committee stressed to you that the MCA does not allow for relatives to act as 'proxy' respondents for residents. Relatives can give their own opinion but cannot speak on behalf of residents lacking capacity to consent.'* (Social Care REC decision letter 17/02/2011, p3) and our application was refused.

The rejection of the initial proposal forced us to reconsider the study. We did not have the time and resources to re-apply with a different design and therefore decided to adapt the design to *exclude* those without mental capacity to consent to the research, allowing us to seek ethical approval from Cardiff University (which was granted). We redesigned the study so that rather than including relatives with a focus on them assisting residents to participate, we decided to include relatives in their own right. Subsequently this helped us to focus on encouraging relatives to talk about what is important to them. "Tell me about what is important to *you*?" has proven to be an extremely powerful question to relatives.

2.3 Sampling Criteria

For this research project, statistical representativeness was not required; however, what was crucial as discussed above was inclusion and the ensuring that as many residents and relatives as possible were provided with the opportunity to participate in the research if they had the capacity to consent to do so. The aim was to include people who might bring different perspectives to the research question. Therefore, it was felt that not only current residents and relatives would be able to assist in the answering of the research question but also those who had been in a participating neurological centre and recently discharged (within one year) would be able to contribute significant data.

Owing to the symptomatic nature of many neurological conditions, there was the possibility that participating in a focus group would be cognitively, socially or practically difficult for some participants. As a result, in order to ensure the wellbeing of all participants and quality data collection, inclusion/exclusion criteria were formed by the research team.

The criteria looked at three main areas: cognition, communication and current place of residence (meaning current inpatient or discharged). (See Table 1.) All participants who did not meet the inclusion criteria for participation within a focus group were offered an interview.

2.4 Group Composition

It is generally recommended to aim for homogeneity in each focus group in order to allow participants to explore, and build on shared experiences in their discussions and in order to avoid hierarchies stifling the free exchange of ideas. With this in mind, it was decided that the groups should be arranged into three separate group types: current residents, relatives and leavers (residents who had been an inpatient within a participating neurological centre for three months or more and had been discharged home or to another care provider). Three or four people participated in each focus group (excluding the facilitator).

Details regarding how questions were designed and groups and interviews conducted can be found in the appendices. (Please see appendix A).

Table 1 – Focus Group Inclusion/Exclusion Criteria

Group	Inclusion Criteria	Exclusion Criteria
All Groups	<ul style="list-style-type: none"> ■ Individual who has no or mild cognitive impairment (must score 24/30 or above Mini Mental Score). ■ Individual with a neurological condition. ■ Individual that can communicate independently either orally or with a communication aid. ■ Individual who has the mental capacity to consent to the research. 	<ul style="list-style-type: none"> ■ Individual with moderate or severe cognitive deficit (scores 23/30 or below Mini Mental Score) ■ Individual who requires assistance to communicate. ■ Individual who does not have the mental capacity to consent to the research.
Leavers	<ul style="list-style-type: none"> ■ Individual who has been an inpatient at one of the three neurological centres enrolled in the research for a period of three months or more and been discharged from the inpatient service and returned home or to another care provider within the past year. 	<ul style="list-style-type: none"> ■ Individual who was currently an in-patient. ■ Individual who was discharged over one year ago.
Residents	<ul style="list-style-type: none"> ■ Individual who is a current inpatient resident at one of the three neurological centres enrolled in the research. 	<ul style="list-style-type: none"> ■ Individual who has been discharged.
Relatives	<ul style="list-style-type: none"> ■ Individual who is a relative or partner of a current resident at a participating neurological centre. 	<ul style="list-style-type: none"> ■ Individual whose relative or partner has been discharged.

2.5 Recruitment process and informed consent

All residents and their families in each of the three participating neurological centres were given an information leaflet detailing the purpose of the research and how to volunteer for the study. The leaflet also stated *'This study has not been approved under the Mental Capacity Act for people without capacity to consent for themselves. Any replies received on behalf of someone without capacity will be excluded from the research study. However the research does include the views of carers or relatives about their own experiences.'* This statement was important in order to be clear to participants from the outset of the limitations of the study.

For all residents and leavers volunteering for the study, the inclusion/exclusion criteria were applied by clinical members of the research team in a one-to-one consultation with each volunteer. The consultation commenced with discussion regarding the purpose and scope of the research, followed by the participation details. Volunteers were invited to ask any questions. The volunteers were provided with explanations of what the inclusion/exclusion criteria contained and how they would be applied.

Explanations included details regarding the Mini Mental Score (MMS), how it would be tested and why it was necessary within the context of the research, and participants were provided with further opportunities to ask any questions.

Communication ability was discussed with the volunteer if required and assessed during the consultation. All volunteers could communicate verbally and all volunteers scored 27 or above on the MMS and were provided with their score.

Following the completion of the MMS, the volunteers were asked to summarise their understanding of the research from the conversation held a few minutes before in order to ensure that the participant had an understanding of the research before commencing the consenting process. No participants without mental capacity volunteered and no volunteers were excluded from the study. However, several volunteers did not meet the inclusion criteria for participation in a focus group; they were therefore offered and accepted an interview and some opted to be interviewed by choice. (See Table 2.) Following the application of inclusion/exclusion criteria, informed consent was gained from all participants prior to data collection.

Relative volunteers were provided with the same level of information as provided to residents and leavers, the inclusion/exclusion criteria applied and informed consent gained. All relative volunteers were able to communicate independently and none were excluded from the study. Several relatives, however, were unable to attend focus groups and opted to be interviewed.

In addition, on the days that focus groups and interviews were held and a week prior, posters were put up around the centres informing anyone visiting that day that the research was occurring and inviting potential participants to drop in to discuss participation with the research team. Several relatives did drop in to volunteer from this form of recruitment. They were provided with the same level of information and informed consent gained.

The approximate number of residents within the participating neurological centres at the time of recruitment was 132. A significant proportion of residents across the three sites were immediately excluded due to either lacking mental capacity or because they were in vegetative or minimally conscious states.

2.6 Overview of the research participants

Relatives: Overall, 22 *relatives* volunteered for the study. None were excluded but three did not participate due to being unable to be reached for interview or because they were unable to attend the focus group and did not wish to be interviewed on their own. Eleven relatives participated in focus groups, two were interviewed in a pair interview and six were interviewed individually.

Residents: In total, 13 *residents* volunteered. None were excluded from the study, six participated in focus groups and seven were interviewed.

Leavers: Three *leavers* volunteered. None were excluded but only one was interviewed (the second did not reply following recruitment and the third volunteer sadly died before an interview could be arranged).

Table 2 – Participant Sample

	Residents	Leavers	Relatives
No interviewed	7	1	8
No participation in focus groups	6	0	11
No participation	13	1	19

2.7 Division of labour among the research team

The research team was led by Julie Latchem and Jenny Kitzinger. In addition, Katherine Juggurnauth (Senior Physiotherapist) co-ordinated recruitment at two sites and facilitated one focus group and James Mitchell (Physiotherapist) conducted one focus group and two interviews at one site. All other focus groups and interviews were conducted by Julie Latchem or Jenny Kitzinger.

Discussion was held among the research team members with regards to the most suitable facilitators for each focus group (for significance of facilitator skills and persona, see Barbour and Kitzinger, 1999, p13&14), considering the direct influence of some of the researchers who were also members of staff at the research sites (see Morgan & Kreuger, 1993; Gibbs, 1997), the practicalities and needs of residents.

2.8 Theoretical/Analytical approach

Prior to data collection, the research team identified that an analytical approach encompassing thematic analysis and elements of grounded theory would be used to manage and analyse the data. Such analysis *'...moves iteratively through stages of data management, description and explanation via a series of 'platforms' from which the researchers can reflect on what they have done and move forward. This process is fluid and, crucially, non-linear; the researcher develops the analysis by moving backwards and forwards between the original data and the emerging interpretations.'* (Pope et al., 2006, p.67).

Such a process requires frequent discussion and collaboration between the research team members and due to practicality of distances involved and the requirement for on-going analysis over many months. This level of contact could be committed to only by the chief investigators; Julie Latchem and Jenny Kitzinger. However, the team members who had helped with data collection were able to meet with the lead investigators immediately after running sessions to reflect on the experience of the group and their sense of the data.

Thematic analysis, in its simplest form, is a method of which identifies and establish themes or patterns within the data and, as highlighted by Pope and Mays (2006), is popular within qualitative health care research. Braun and Clarke (2006) argue that although thematic analysis is *'rarely acknowledged'* it should be considered to be a *'...foundation method for qualitative analysis.'* and state that *'Through its theoretical freedom, thematic analysis provides a flexible and useful research tool, which can potentially provide a rich and detailed, yet complex, account of data.'* (Braun and Clarke, 2006, p.78).

The thematic analysis methodological approach can be realist, constructionist or contextualist. The realist method seeks to report *'...experiences, meanings and the reality of participants.'* The constructionist method *'...examines the ways in which events, realities, meanings, experiences and so on are the effects of a range of discourses operating within society'* and the contextualist method sits *'... between the two poles of essentialism and constructionism, and [is] characterized by theories [...] which acknowledge the ways individuals make meaning of their experience.'* (Braun and Clarke, 2006, p.81). The analysis and subsequent reporting presented here takes a primarily realist approach and, due to the professional and personal experience of the research team, much contextual consideration was given to the data and has been incorporated.

Thematic analysis was the primary analytical method undertaken but data analysis via elements of grounded theory approach was conducted throughout the project, the researchers sharing and discussing their own current perceptions prior to data collection and their impressions of data post collection, un-picking key elements or emerging themes and exploring these in more depth through facilitation in later data collection.

Grounded theory, '*...in contrast to theory obtained by logico-deductive methods is theory grounded in data which have been systematically obtained through 'social' research.*' (Goulding, 1999). An element of grounded theory used was open coding. Open coding is '*...the process of breaking down the data into distinct units of meaning.*' (Goulding, 1999, p.8). This, backed by the making of 'memos', (notes to self) immediately post data collection, was utilised in this study. Such memos were simply the researchers' impression of the data recorded post data collection, i.e. following the facilitation of a focus group. These effectively act as a memory bank and are incorporated into the data, aiding data analysis at a later date, as initial impressions were used to capture possible insights but were also subject to systematic testing as analysis was conducted across all the data sets.

Owing to the subject matter and the research focus being to inform providers, the research team were also interested to investigate what clinicians working within the environment of the study population thought. During data collection days the research team invited comment from health care professionals on site and asked them to perform the same task as designed for the focus group, rating the set of pre-written cards and discussing their reasoning with the researchers.

Notes made by facilitators during and directly following the data collection were transcribed by Julie Latchem.

2.9 Data management and analysis

Once all data were collected, data management commenced. '*The first task in the analysis is simply to manage and make sense of the huge array of data collected*' (Pope et al., 2006, p.67). All audio recordings and notes were transcribed. Julie Latchem and Jenny Kitzinger initially read and re-read the data in order to become familiar with all of it. Notes were made on the transcripts and initial categories highlighted by the researchers independently. Discussion was then held between principle investigators and more in-depth thematic analysis commenced.

Data from residents and relatives were initially managed as separate bodies of data. It was important to treat this separately in order to be able to identify what was distinctly important to both groups and to allow another layer of analysis into the research through identifying similarities and differences. Data analysis commenced with residents' data as it was crucial to keep residents at the centre of the research. From the central components identified from residents' data, relatives' data were subsequently analysed and the context broadened.

An index was produced of all topics identified as important by the participants, systematically noting where such comments occurred and with quotes being pulled from the transcript. '*The data are systematically searched for reoccurring themes*' (Pope et al., 2006, p.67). Crucially, the researchers do not just look at reoccurring themes but also '*...views that are unusual [...] or contradictory.*' (Pope et al, 2006, p.67).

Initial categories were considered for grouping and establishing key themes through an inductive, latent thematic analysis. Themes are defined as capturing ‘...something important about the data in relation to the research question, and represents some level of patterned response or meaning within the data set.’ (Braun and Clarke, 2006, p.82). Once themes had been identified they were cross referenced by the original index, the context and how the information offered reflects what the participants were trying to say to the researchers. ‘...the researcher groups the data into themes, and examines all the cases in the study to make sure that all the manifestations of each theme have been accounted for and compared.’ (Pope et al., 2006, p.69).

In addition, returning to the initial hypothesis, consideration was given to how, if any, perceptions of health care had been *inadvertently* displayed by participants and how this may have affected the data. Thematic comparisons were then made between both sets of data and, as required, more in-depth analysis carried out using key sections of the original data. Data were pulled from transcripts, considered and coded for content and originator (see Figure 1). Data were then cut into separate pieces to be analysed individually (see Figure 2). Although there are computer programmes designed to facilitate such analysis (e.g. the Nudist programme), we preferred to work with colour coding and visual/special methods.

Relatives’ data analysis in progress:

Figure 1:



Figure 2:



2.10 Presentation of data and confidentiality

Significant care has been taken to maximise the confidentiality of study participants. In order to achieve this, pseudonyms (fictitious names) or just pronouns have been used for people. We have used first names as this is how most participants introduced themselves to us. Places have been referred to as either acute hospitals, rehabilitation centres or neurology centres. Setting specific identifiable information has, where required, been removed. On occasion, quotes are unattributed or genders may have been changed.

2.11 Missing voices

While the focus of this research has been on inclusivity, it does not represent everyone. As already highlighted, we did not include those without capacity to consent to the research on their own behalf – we hope that future research might be pursued to fill this gap. In addition, inevitably some people were more likely to volunteer than others – e.g. relatives who were not closely involved with the care centre were less likely to volunteer for our research. Similarly, there are lots of demands on relatives that meant that some who might have liked to participate were simply under too much pressure to spare the time. We would also note that this research is focused on rehabilitation and long-term care in residential centres. Many people with neurological conditions are cared for at home – and this is a long term care setting in its own right, one that is often ignored and neglected for research. The perspectives of these services users is also key for future research.

Navigating the Report and How the Data is Presented

The voices of 33 people and their conversations with us over 20 hours provided rich and detailed data; ensuring we do justice to the data but unable to detail it in its entirety, we present our *key* findings in this report. During data analysis and in the writing of this report, we have been led primarily by residents' data, keeping them central at all times. Residents' and relatives' data were analysed separately, being brought together only after the establishment of key themes. Only after key themes had been identified did we decide that the evident mirroring of themes, issues, thoughts and feelings between the data sets justified the joint presentation of both data sets throughout the report.

3.1 What is 'most' important?

What residents said was important to them and what relatives felt was wanted and needed by their loved ones mapped closely. Residents often raised *first* that therapy and more specifically physiotherapy was important to them. What was raised first as important to relatives was more varied but was one of the following four things: the importance of homeliness within the long-term setting, the need for rehabilitation (therapy), stimulation for residents on a day-to-day basis and the importance of good information sharing with them.

The strongest theme in both sets of data was relationships - with both residents and relatives, placing great emphasis on the importance of their relationship with staff. Residents primarily highlighted the importance of their relationship with nursing, care and therapy staff whereas relatives highlighted the importance of the relationship with all long-term care staff including administrative personnel, catering staff and doctors.

3.2 Similarities and differences

Relatives participating in this research had family members with varying levels of physical and cognitive disability and with differing prognoses. Two-thirds of the relatives who participated in this research had loved ones who did not have the capacity to participate in the research themselves under the ethics approval we have been granted; some of these residents would not have been able to contribute to research on their own behalf anyway because, for example, they were in a minimally conscious state.

The relatives' data differs thus from the residents' data on *two* counts – firstly, because they are speaking from their perspective as a relative and, secondly because they are often reflecting on a loved one with more severe physical and mental impairments than the residents who participated in our research.

Relatives, however, were not included in the research to speak 'on behalf' of any resident but were invited to speak on their *own* behalf about what was important to them about long-term residential care – and this was emphasised in the information they were given about the research project. Not surprisingly, however, many of the issues raised by relatives focussed on the nature of care given to their loved one.

Residents and relatives often identified the same key things to be important but for differing reasons or viewed them differently due to their particular perspective. This is best demonstrated through the series of tensions that arose from the data and are presented in the report following the key findings.

3.3 Key Themes

The data were grouped into seven themes on the basis of the analytical process detailed in the previous chapter. The seven key themes were:

- Chapter 4 - Relationships
- Chapter 5 - Physicality and physiotherapy
- Chapter 6 - Independence and activities of daily living
- Chapter 7 - Stimulation and activity
- Chapter 8 - Security
- Chapter 9 - Connectedness and information
- Chapter 10 – Environment

Chapter 11 explores some tensions in the data and Chapter 12 examines some needs and concerns specifically highlighted by relatives. Relatives highlighted some areas in slightly different ways than the residents who participated in our research and raised some additional issues. For example; relatives identified their need to be part of a team caring for their relatives and for information about what was being done for/to their relatives; they highlighted the importance of a more diverse range of therapies in addition to physiotherapy and raised particular concerns about medical decision-making. Relatives emphasised their own needs for inclusion in the community of the care home as well as discussing challenges they faced as the family of someone with care needs.

Residents' Relationships with Staff, Each Other and Family Members

One of the strongest findings from our research was the importance residents and relatives placed on the quality of residents' relationships with care and therapy staff. This was often the very *first* thing mentioned in our interviews and focus groups with both residents and relatives and was repeatedly underlined. Value was also placed on relationships between residents and other residents (particularly by residents) and between residents and their families (particularly by relatives).

This chapter outlines the importance placed on good relationships and positive interactions, and what was meant by a 'good quality' relationship.

4.1. The importance of residents having good quality relationships with staff -

4.1(a) Residents' views

'Everything should be done with care by carers.'

Residents describe how much they valued staff being 'friendly' and 'caring'; they highlighted the nature of their relationship with staff as being one of, if not *the* most important part of their experience of long-term residential care. 'Erica', for example said:

'For me it's the most important part of me being here. [...] I don't think I would have stayed fifteen months had I not thought, look, I know you're not supposed to say they're your friends.' (FG2, Erica)¹

¹ Pseudonyms (fictitious names) have been used for people and places. FG indicates that a quote was taken from a Focus Group. INT indicates that a quote was taken from an interview. First name pseudonyms have been used as this is how most people introduced themselves to us. In some cases in order to maximise confidentiality quotes have been left unattributed, genders changed or participants referred to as 'Resident A, Resident B'.

Friendliness and caring: residents refer to time with staff and talking to them as individuals rather than in their professional roles as important and as a part of their social life. For some residents, staff being deemed to be 'normal' or 'real people' was key. Patrick commented: *'They're real people.'* (FG2, Patrick) and Max explained; *'They're all individuals, at the end of the day I think that helps massively.'* (INT8, Max). Having fun with staff and mutual enjoyment of each other's company was expressed to be extremely important. *'I think having a laugh with the staff [is important] more than anything.'* (INT8, Max)

Residents made comments that related to the welfare of staff and demonstrate a deep connection and consideration for those that care for them on a professional basis. They were concerned if they felt staff were mistreated – by other residents (e.g. *'What I don't like is she is very rude to carers and staff.'* (RINT, Denise) – or if they saw staff placed under stress (e.g. *'It's not fair the staff shouldn't have to [work short staffed].'* (FG2, Patrick)

Residents wish for staff to 'care' for them as denoted by their job role but also to 'care' emotionally. They made comments such as *'[it's important to have] people that care for you if you know what I mean, in an emotional way.'* (INT8, Max) and discussed the importance of being emotionally supported by staff on a day-to-day basis. Marjorie explained:

'You've got somebody to give, give you confidence and to help you with any problems [...] someone to confide in if you are worried about something.' (INT1, Marjorie)

Residents deem staff as a very important part of the fulfilment of their emotional well-being and highlight the support and encouragement staff gave them, especially during times of difficulty.

Recognised as an individual: residents also talked about the value of being well known by staff and being treated as an individual. This incorporated wanting to be known personally (i.e. their personal traits, likes and dislikes) and functionally (i.e. staff knowing care routines and any functional limitations) in relation to enabling them to maintain their own individuality.

'Knowing your resident [is important], they [staff] may say to you "Are you ok?" and your resident will say "yeah" and you're not, they have to know. Some carers here know me inside out.' (INT7, Denise)

'The other thing to add is that they [therapy staff] understand our needs on an individual basis. You're not just another person, you're very much an individual that they understand.' (FG2, Arthur)

'...you're given a lot of time by the staff I think, like [...] they help me put body cream on, make sure I've got all my toiletries on, I really think they go the extra mile to make sure you have everything you need.' (FG2, Erica)

Professionalism, trustworthiness and respect: although residents report benefitting from relationships with staff that exist on the edge of professional confines, they do also require professional boundaries to be maintained. The approach of staff and staff professionalism was a pertinent issue for many research participants. Positive and negative examples were provided. For several residents, the way they are approached by staff, staff attitude and the delivery of what they perceived to be appropriate manners were important.

'Respect of the carers [is important] [...] keeping to their word when they say they're going to do something, they keep to their word, not "oh we'll do it tomorrow, oh we'll do it next week."' (INT7, Denise)

'Carers should not chew gum, if someone comes up to you chewing gum it's rather off putting and sometimes they drink from a can, right in front of me.' (INT1, Marjorie)

Max provided a particular example of a good approach from staff while he received passive range of movement and stretches:

'If I was watching the telly they'd [therapy staff] say don't turn that off keep watching it and they'd be there supporting you in a very unobtrusive way, which was: you could interact with them if you wanted to or just close your eyes.' (INT8, Max)

Residents also commented on how they felt it was important for staff not to hold conversations between themselves while doing interventions. Interactions where staff did not display interest or care were a source of unhappiness or criticism. Although applied only to a very small minority of staff, residents commented that they hated it when staff were 'dismissive' and 'don't listen'. One group, for example, discussed the lack of time a doctor might have for them, and the way hierarchies could get in the way of what they wanted.

Resident A: *...the nurses take orders from the doctors even though, say they [nurses] might perhaps know you better I think [...], myself I've had a nurse in my room and she's tried to tell a doctor something on my behalf because they feel that the doctor isn't listening to me and the doctor just completely dismissed the nurse.*

Resident B: *It's like the doctor is God.*

4.1(b) Relatives' views

'...all we want them to do is just care.'

Mirroring the sentiment expressed by residents, relatives specified how imperative it was to them that staff cared for their loved ones emotionally as well as physically - as Lois commented *'I am very clear I want staff who are going to engage at the heart not just the head.'* (RTFG2, Lois) Relatives placed great importance on the way in which staff related to their loved ones, highlighting the importance of a positive and caring atmosphere being created by staff and their interactions with each other and with residents.

'Here we had a fantastic manager on the first floor, he was bright he was breezy, he was cheerful and absolutely a ray of sunshine, and obviously his staff were more like that as well and you'd come in and there would be a carer sitting just stroking somebody's arm whose in a wheelchair, [...] or somebody reading to somebody.'

Relatives also identified the importance of residents having positive and personalised interaction with staff.

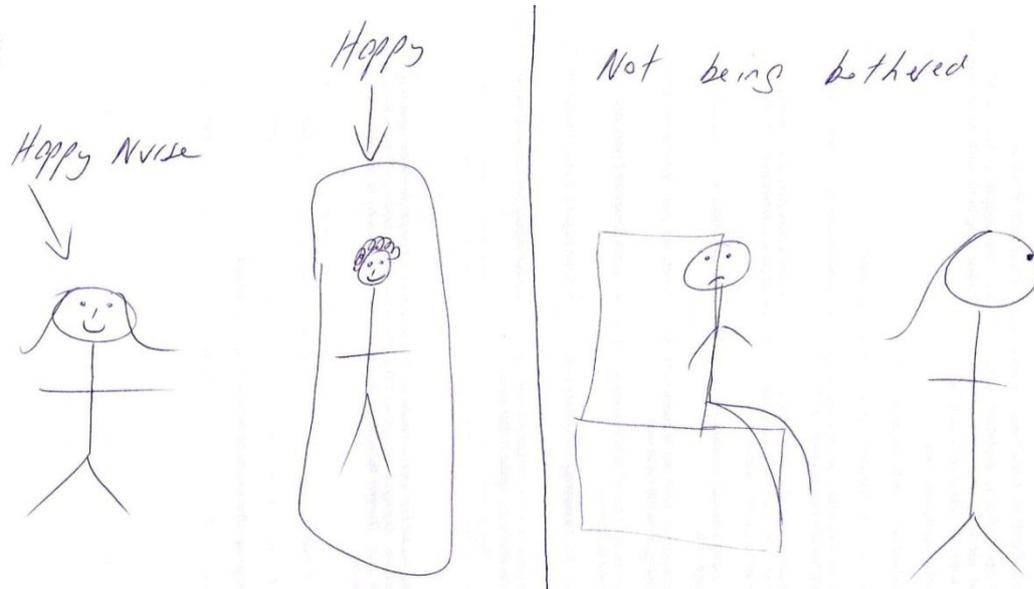
'Adjusting to the individual is very important. As the public we think people with brain damage are kind of goofy sitting in a chair and you feed them and talk to them in loud simple sentences. And they are all so different.' (RTINT3, Grace)

'Some of the times at [hospital] the young ones, when they were changing her were talking to each other about boyfriends, and mobile phones, goodness knows what, where with these staff [at the Neuro Centre] I feel [they] do actually chat with her [...] engage with her properly, [...] as a person.' (RTINT2, Judy)

As Lois commented:

'...the staff have to get into the shoes of that person or the soul of that person to really understand where they are coming from.' (RTFG2, Lois)

Illustration 1: A relative's drawing of what constitutes 'good' care (left hand side) and 'bad' care (right hand side).



Staff being happy, positive and interested in residents is depicted here as defining 'good care'.

Several relatives highlighted how important it was that their loved ones could trust staff. Henry explains:

'...it was very important that Marion could trust the team. It wasn't a question of whether they were capable of looking after her but did she trust them to look after her; that was the most important thing.' (RTFG3, Henry)

Like residents, relatives were also concerned if they felt there was a shortage of staff as this impacted on care:

'[If they are] short staffed, all they can do is take care of bodies.' (RTINT2, Judy)

As well as the appropriate number of staff – relatives also highlighted the importance of continuity of staffing. Continuity of staff was seen as an important factor to improve internal communication, *"Our worst scenario would be if a manger changed."* (RTPINT1, Martin) and to allow the opportunity for relatives and residents to get to know staff and therefore develop a sense of community. Relatives believed that staff continuity also improved quality of care. Added to this relatives raised the need for keyworkers.

"The other thing I'd like to see [is a] key worker. [...] I want to talk about is how [relative] is doing in this area and if that key worker doesn't know that question about physio then let them put that question to physio." (RTFG3, Henry)

The personal and professional qualities that staff brought to their work with residents were highlighted as one of the most significant aspects of good care. Maggie commented:

'Most people have a calling. I still think carers should get properly paid for the work they do, [...] It's such an important job, caring to me, well, it's got to be one of the most important jobs anyone can ever do. We're entrusting our loved ones, aren't we, to people and we just hope that they are doing, and I'm sure they are doing, everything they possibly can.' (RTFG3, Maggie)

Maintaining their loved ones' dignity within the long-term care setting was an important issue for several relatives. Most relatives felt that staff are considerate and did preserve residents' dignity. As Fran commented:

'If he could verbalise he would want to be private and to be fair the carers are always very good and draw the curtains [...] They will always knock on the door and if they are right in the middle of cleaning him up they will immediately cover him over so they are very good, [...] and making sure that his clothes are clean and if he dribbles and his t-shirt gets wet they'll change that. To me it is important because, I think, I wouldn't take him out looking a mess [...] Respecting the fact that he is a young man and he can't do anything for himself and he can't express anything but there is still a person in there.' (RTFG1, Fran)

Simon, however, commented that he felt greater consideration could be shown at times.

'I want to feel that he has dignity about what he is doing, [...] we constantly report to the home about their shrinkage of his clothes, [...] at times he's been dressed in clothing which has been shrunk and is clearly too tight for him [...] he's got nice clothing and you continue to ruin it, there's not that wrap around care like if you went to an old aged persons home or something, you'd expect them to put some care into clothing and other bits.' (RTINT1, Simon)

Relatives recognised, however, that dignity meant very different things to each person.

'Dignity, very important. I have mixed feelings. Malcolm couldn't give a hoot and never has done whether someone sees him in the altogether [...] it was never an issue with him [...] difficult for me because I think of dignity being the curtains pulled round if you are getting changed [...] to be fair the carers are always very good and draw the curtains [...].' (RTFG1, Elaine)

4.2. Residents' relationships with each other

4.2(a) Residents' views

Residents emphasised the importance of their relationships with other residents within the long-term care setting – making regular reference to their enjoyment of socialising with each other and sharing everyday experiences:

'Quite interesting people here. I like to know all about their backgrounds. I like profiles on each one, I find [that] valuable.' (INT2, Jack)

'We all sat round eating it together, sat smiling at each other when the boxes [of takeaway food] came in, it [was] nice.' (FG2, Erica)

They also talked about the possibilities for peer support and advice in order to gain a better understanding of their own injury, what to expect in the future and to share in the experiences of others. Max commented:

'...talking to the other residents who had a similar disability to me, [...] was massively important for [me] [...] To be able to sit and talk things through to them, you know down to the smallest thing, "I've had this twinge in my leg" and one of them would pipe up and say "Yeah I've had that as well and this is, you know, this is what will probably happen next and that is what's caused it" and very much then puts your mind at rest that you know there is somebody else going through it.' (INT8, Max)

Arthur also highlighted how being with others who faced similar challenges reduced their own level of self-consciousness.

'Like for instance I've been a bit concerned about how I was eating and that, whereas being in this environment, with other patients, has made me feel like I couldn't care a damn about it.' (FG2 Arthur)

Several residents identified a feeling of protectiveness towards other residents. Erica, addressing another resident in the focus group remarked:

'...because you've got common bond with patient's straight away so if, I don't know about you but I feel really protective of the other, of the other patients.' (FG2, Erica)

They also expressed how they felt a responsibility to act as a voice for those residents who are unable to communicate.

'[I] want to make sure they are ok especially the ones that can't talk, you sort of feel like you have to be their voice.' (FG2, Erica)

Several residents explained how they had, in essence, built a surrogate family from those around them. As one resident commented:

'You had Emily [resident] and George [resident]; they were kind of your mum and dad.'

Residents voiced how being able to help each other and contribute to community (of staff and residents) was important to them, as was being able to 'take ownership' of some things.

'I was excited [being able to contribute creatively], I was doing my bit.' (INT7, Denise)

'We organized amongst ourselves a take away evening, obviously quite a lot of the patients have money controlled by staff so we just had to ask for the money but it was nice to take ownership of something that was ours.' (FG2, Erica)

4.2(b) Relatives' views

Although not discussing the relationship between residents in such depth, relatives did briefly discuss this issue. They also identified the importance of other residents to them. Talking about the death of one resident for example, one group of relatives commented how upsetting this was for everyone – residents and relatives alike because:

'...he was everybody's friend. He knew what everybody wanted when they couldn't talk and you know, he would ask for them and when he died, it was such a shock.'

4.3 Residents' relationships with their family

4.3(a) Residents' views

Residents sometimes talked about the importance of being able to maintain relationships with their family and have family members involved in and welcomed in the centre. As Max commented:

'It's not just the person who's in here having rehab, who sleeps in here, the kind of whole family go through the rehab as well, I think so, you know for them to come in and be made, "do you want a coffee, bring up a chair and come and watch [therapy]" is great.' (INT8, Max)

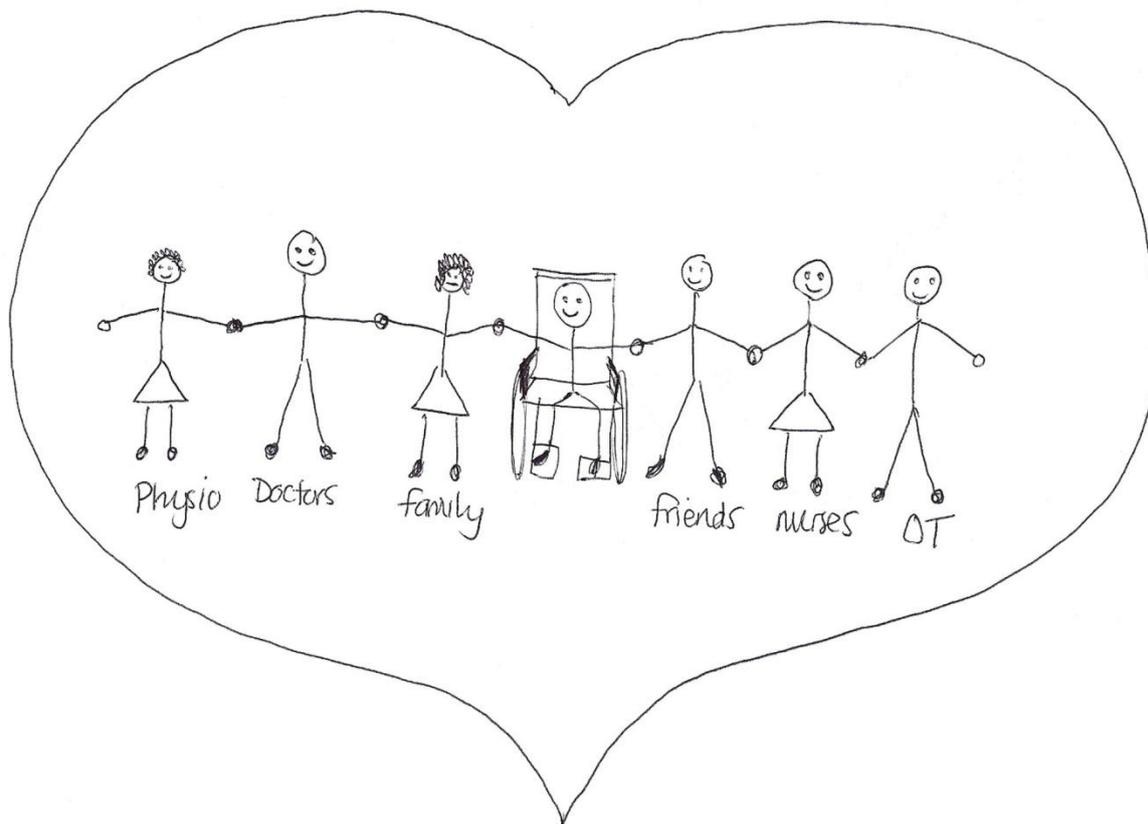
One resident also emphasised the importance of a centre which welcomed children:

I wasn't made to feel as if the kids were in, in the way or messing around and I think that, you know possibly some of the other residents and some of the staff enjoyed seeing the kids as well at the same time so it was nice.'

4.3(b) Relatives' views

Relatives placed particular emphasis on the importance of the long-term care setting helping them to maintain a relationship with their loved one. These needs encompassed their own and that of the family to feel welcome and included in the community of the centre (and is further discussed in detail in Chapter 12). *'The fact that they have opening visiting hours is the first thing, you feel like you are welcome.'* (RTINT3, Grace) commented Grace, while Elizabeth commented *'...when you walk through the door you're not this unknown person, it's like an extended family almost.'* (RTFG2, Elizabeth)

Illustration 2: A resident's drawing depicting 'good care'.



Residents' Physical Care and Therapies

Residents highlighted the role their bodies have in contributing to their feeling of well-being and talked about the importance of good care, physical comfort and the emotional impact of touch. Residents highlighted the importance of being handled correctly by health care workers and discussed their feelings about being moved and being able to move themselves. Relatives, like residents, discuss the importance of physical care and therapy but also consider in particular, the importance of medical care.

5.1 Physical care needs

5.1(a) Residents' views

Residents emphasised the importance of having physical needs met in a timely manner for comfort or to reduce the impact disability has in relation to their ability to engage in meaningful activity.

'The day time staff are marvellous [...] the night time staff keep you waiting a bit longer when you press the buzzer.' (FG1, Joe)

'[It's important] Being able to be got up at the timing that you want, approximately.' (FG2, Arthur)

Residents made reference to the requirement for the right number of staff and staff availability in order for this to be achieved, for their needs to be met quickly. Patrick commented:

'It's low sometimes. As long as the staff that are here are good, which they are, we cope.' (FG2, Patrick)

5.1(b) Relatives' views

Like residents, relatives emphasised the importance of their loved ones' physical needs being met. Many detailed how important it was that their relatives received good standards of physical care in order for them to remain comfortable.

'Once a physical need dominates [...] it just becomes paramount and you can't think about anything else until it's been dealt with.' (RTINT2, Judy)

'Skin integrity [Is very important], because it highlights other problems with care. If you cannot keep someone physically intact they will get frustrated and you cannot keep them emotionally intact.' (RTINT3, Grace)

Unlike residents, relatives raised the importance of good medical care. This was, for some, considered crucial and identified as a fundamental consideration of placement.

'First criteria has to be, "Does it meet medical requirements?"; we have to have that platform, if it doesn't meet medical requirements then there's no point in even looking at it.' (RTFG2, Lois).

Relatives voiced the importance of having skilled and competent staff with specialist neurological skills caring for their loved ones.

'Long-term treatment, it's vital and it has to be done by people who know what they're doing.' (RTINT4, Ray)

Over and above this, however, several relatives expressed that although medical care was important, the meeting of residents' emotional needs was equally as important. In considering the physical focus of medical care they also discussed how this either impedes or facilitates their loved one having their overall 'holistic needs' met. Judy explained:

'[the] model that focuses on emotional health and mental health, [...] is at least as important as caring for bodies [...] I suppose I relate it to hospices and stuff [...] once they [hospice staff] accept that medical science is not going to do much more with the body they start putting a heap of emphasis on a person being able to deal with other stuff. [I prefer][...] more of the hospice model that focuses on emotional health and mental health [...] the person is [not] the body, [...] so keeping the body going is not of paramount importance.' (RTINT2, Judy)

5.2 Therapy

5.2(a) Residents' views

Physiotherapy was regularly emphasised by residents to be crucial to them and was the most frequently mentioned therapeutic profession. Physiotherapy was often raised as the *first* thing of importance in the initial response to the main research question and was also considered by some to be the *most* important. Residents reported finding the contribution physiotherapy makes in restoring function, the relationship with their therapists, physical touch and the ability to move or to be moved and sense of achievement as important and beneficial. Erica and Jean commented:

'Yeah, definitely physio, number one, it's what obviously separates it from being a care home to rehab, so physio definitely, top priority.' (FG2, Erica)

'It is a long haul. But yes I think that [physiotherapy] has helped more than anything.' (FG1, Jean)

Residents raised the importance of the resident–professional relationship being based on trust.

Erica explains:

'If you can't trust your therapist, [...] I know, obviously [the therapy] comes before a relationship but I think the relationship actually comes first, you need to be able to relax and trust what that person's doing.' (FG2, Erica)

Arthur reiterates:

'You need to build that bonding as it were.' (FG2, Arthur)

Residents expressed how they felt listened to by therapy staff. Patrick commented: *'They understand that we want to do as well as we can. We don't just want to put up with it, we want to enjoy it and get it done.'* (FG2, Patrick) and Arthur highlighted how therapy staff make treatment sessions enjoyable. *'... the staff make it [physiotherapy] fun here.'* (FG2, Arthur)

Residents commented how feedback from therapists during therapy sessions was important and how critical the analytical skills of therapists in aiding rehabilitation were. Max discussed feedback following physiotherapy:

'It's always positive and not criticism but it's almost like having a debrief after your physio, [...], if you're not bending your knee enough or something they'll pick it up.' (INT8, Max)

All residents who made comments regarding physiotherapy felt it was helpful, or had been helpful in the past, and no negative comments were made about the delivery of physiotherapy or any other therapy. Residents identified regular therapy as being important to them and some felt they would like to receive more. *'I like physio five times a week but at the moment it's four or five.'* (INT2, Jack)

Residents also connected therapy to assisting them in having goals and providing a sense of achievement and *'a goal to aim for.'* (FG2, Patrick) Some residents even considered the receipt of physiotherapy to be the main purpose for their admission.

'Because basically, from my point of view [...] the pure reason for being here is having physio.' (FG2, Arthur)

Residents discussed the positive impact of physiotherapy on their sense of physical well-being and contrasted this with how they felt when there was a break in physiotherapy provision.

'...last couple of weekends have been bank holiday weekends [...]. I've found that really frustrating and I noticed it in the body as well. The body has just stiffened up completely.' (FG2, Arthur)

'...or stretches in the morning as well it just absolutely must, critical in the early days as well. It just, that kick start of the day. I used to find mornings very, very difficult, more so in [the hospital] than here but mornings for me were just a complete nightmare.'

5.2(b) Relatives' views

The importance of therapy was discussed in all relatives' focus groups and all interviews; staff with specialist neurological skills were seen as key for understanding and progression.

'Whilst she was at [The Neuro Centre] I was very impressed by the occupational therapist, the physiotherapists and the speech and language therapist, I thought they were excellent.' (RTINT4, Ray)

'It was one of the reasons we chose for him to come here [physiotherapy] because if he had been out in the community [...] he would not have got the physiotherapy service.' (RTFG1, Fran)

'Since the three years since her [injury] she has had three periods of rehabilitation [...] and saw OTs and physios there and clearly made progress but when she came home she went backwards.' (RTINT4, Ray)

Like residents, they also wish their loved ones had or could have more therapy.

'The qualified staff they have there I have no criticism of at all, [...] they struck me as being very good but they didn't see Patricia often enough and she needed more stimulation.' (RTINT4, Ray)

'Definitely not enough physio [...] Leo [only] gets that three times a week, Monday, Wednesday, Friday for an hour a day if he is lucky' (RTPINT1, Martin)

Grace detailed how the *approach* therapists took was important and how it differed from other health care professionals.

'I think the OTs and speech and language [therapists] have to work with what they've got. [...] they're not steamrolling, they're not, they've been quite adaptive with her [resident] by backing off and saying maybe a schedule of therapy is not what she can co-operate with and we need to adapt it to her psychology a bit [...] because they have to work with difficult patients often to do things to someone that's painful without giving them anaesthetic to do it. They need co-operation...' (RTINT3, Grace)

Others highlighted the wider benefits that can be provided by therapy.

'It's [physiotherapy] keeping Luke as stable and as well as possible you know, it's helping him with his breathing, getting him out in his wheelchair is preventing pressure sores [...] it's maintaining him at his level [...] If he didn't have it he would go downhill, I'm certain of that.' (RTFG1, Fran)

5.3 The impact of Touch

5.3(a) Residents' views

Several residents discussed touch, the different sources of touch they receive on a day-to-day basis and its impact on themselves and others. The quotes below express the emotional context of physical touch for some residents, how it makes them feel and what it means to them.

'...you soon realise that the equipment is secondary to [...] what the therapists do and I know it sounds stupid but I think touch is, is so important, you see a lot of the residents you wonder how much touch they have in a day like, I don't mean people rolling them and wiping their bums, I mean proper love and affectionate touch, I think that's so important for people to feel [pause] like they're loved.' (FG2, Erica)

Patrick said simply: *[Touch helps] 'Just to feel human.'* (FG2, Patrick)

Residents also discussed how they felt when being assisted during personal care tasks. Marjorie explains how she feels and provides an example of her experience.

'The best way [to perform manual handling task], [pause] take it slowly and not to do it quick. Everything should be done with care by carers. At night times the carers are the ones and sometimes they frighten me by the way they grab hold of me.' (INT1, Marjorie)

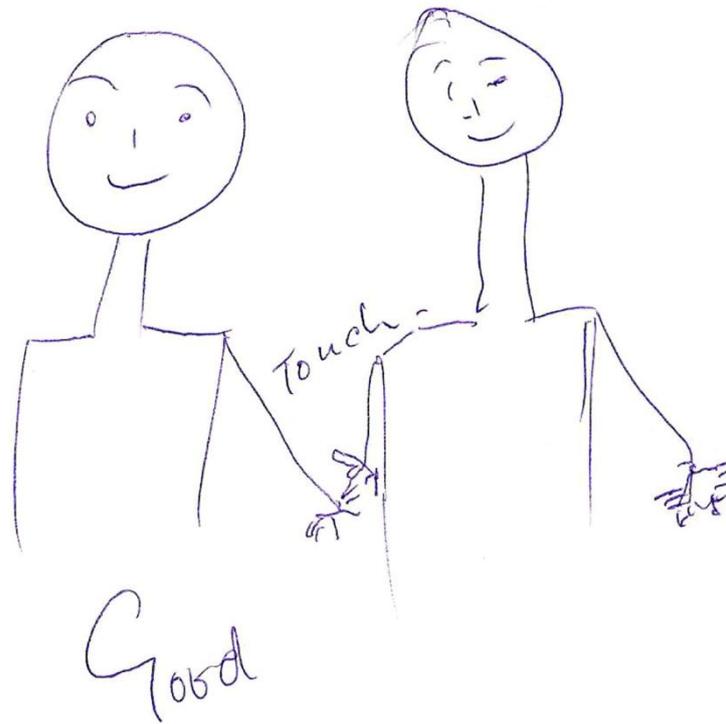
5.3(b) Relatives' views

Relatives did not emphasise the importance of touch as strongly as residents but they did, however, recognise touch as a valuable addition to care and therapy; for example, Elaine suggested setting up massage or aromatherapy sessions – maybe on a voluntary basis.

'I've got a friend who does aromatherapy and she used to come to Malcolm to do his hands and his feet when he was at home and he loved it and it's just that contact isn't it.' (RTFG1, Elaine)

The importance of touch was also raised by one relative through their drawing of 'good care' (see Illustration 3).

Illustration 3: A relative's interpretation of 'good care'.



Independence and Activities of Daily Living

Residents emphasised the importance of being independent, having support and opportunity to carry out normal every day activities, make decisions for themselves, take 'ownership' and 'control'. Relatives considered this element from a perspective of residents' autonomy and having choice.

6.1 Independence

6.1(a) Residents' views

'I think everyone just wants to be in control of their own life.'

Residents talked about independence in the context of being able to carry out activities of everyday living. Independence was also discussed in terms of the impact of either the loss or regaining of it.

'...[from] being independent to being not independent has really taken its toll.' (INT7, Denise)

'I think everyone just wants to be in control of their own life.' (FG2, Erica)

Through discussion of the pursuit of independence, a sense of conflict was generated especially regarding risk taking required in order to regain independence. This is discussed in greater detail in Chapter 11.

6.1(b) Relatives' views

'I just want her to have her life, her autonomy, her independence.'

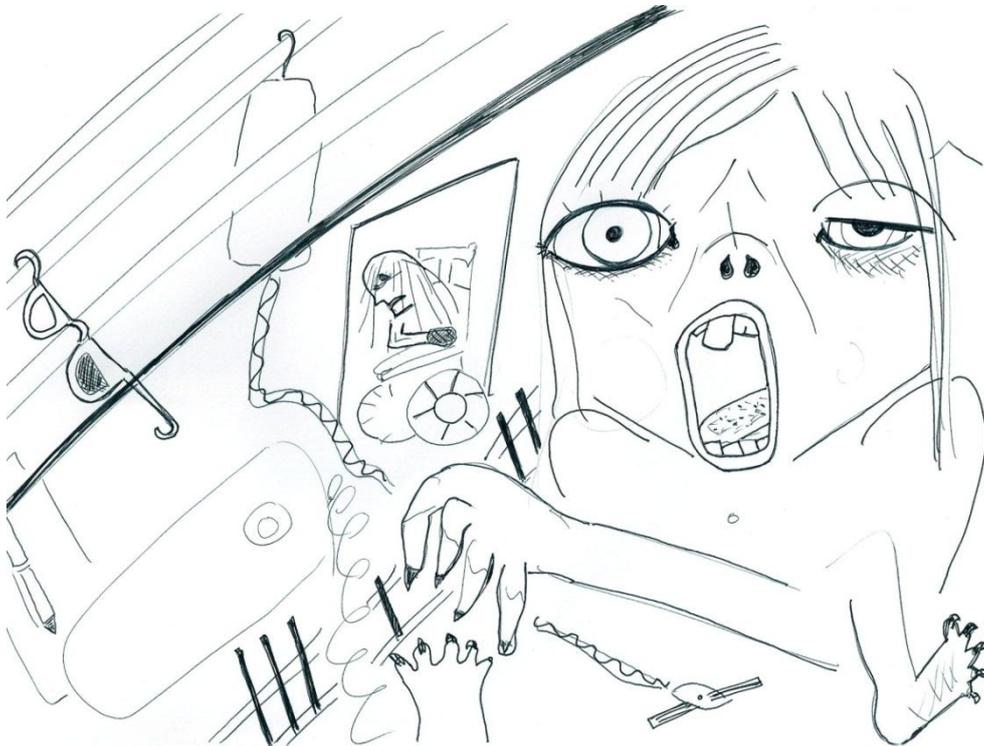
Some relatives, like residents, emphasised the important of residents' independence, having access to and being assisted or facilitated to carry out activities of daily living. Several relatives expressed particularly the importance of choice, the support and facilitation of autonomy for their loved ones.

'They are very good at offering her choice and trying to give her control over things she can control.'

However, as one relative commented:

'I just want her to have her life, her autonomy, her independence and no amount of care can give her that so if they don't put her glasses within reach I get frantic but actually it's the [...] accident that took that [her autonomy] away and I can't expect [The Neuro Centre] to give it back.'

Illustration 4: A relative's picture of 'bad care'.



Relatives also considered the importance of residents being able to communicate independently and discussed how important staff aiding residents ability to communicate is.

‘Relative A: I think from staff in general it’s to be understanding because where, when he first came here, he caught all the problems he had in hospital, i.e. when a nurse comes up and has given you a wash and got you ready, they walk off, they’ve left you without any communication, no buzzer etc. It’s taken ages to get through.

Relative B: *It’s taken us forever...*

Relative A: *Give him the buzzer*

Relative B: *To ram it in to people that that is his lifeline’*

6.2. The importance of everyday tasks and rehabilitation

6.2(a) Residents’ views

The idea of setting and striving to meet goals was raised as important by one resident but, overall, the significance of having purpose, participating and taking ownership seemed to take precedent. Whether this is inclusive of ‘goal setting’ is not clear. For some, having an interest or taking an active role in the management of the centre was one example of providing this extended sense of purpose.

The importance of returning to normal activities was emphasised, as was access to support to enable these activities in a timely manner. As Denise commented, *‘I love my hair being done.’* (INT7, Denise), or described their satisfaction in being able to do key things for themselves: *‘I have a shower once a day. I finished my make-up, I’m very wobbly but I finished it.’*

Residents report being frustrated by not being able to do things they enjoy due to their physical disability but explain that how the carrying out of normal, everyday type activities can make a positive impact on their well-being.

‘I remember when [occupational therapy technician] brought me out of my room and started making me do things, I really started to enjoy myself here and I think because of the variety of things you can do here it makes you, you start feeling more normal in yourself because, you know if you wanted to go to the shop [...] you just got to ask a few people and they’ll say “Yeah come on I’ll take you to the shop” [...] and you go and you’re getting your bit of therapy [...] but also you’re having a bit of you time whilst you’re there.’ (INT8, Max)

Residents also discussed the need to carry out ‘activities of daily living’ in order to prepare for home or independent living and debated what rehabilitation is and what it entails.

‘...but I think rehab is meant to be about getting you back to the community, getting you back to your own home, so this place should be geared up [...] one thing that’s sorely lacking is a kitchen. We should be able to help make our own meals.’ (FG2, Erica)

It is pertinent, however, to note that residents who participated in the research were at different stages of the rehabilitation pathway, not all were ‘actively’ rehabilitating, and some were now outside of the traditional rehabilitation pathway and would always need long-term care. Some, however, had progressive disease and the maintenance of their independence was at the forefront of their minds and of the utmost importance; however, it is relevant to clarify that accessing and carrying out activities of daily living were not raised as being key for all residents. For some, the focus rested more on just being able to get out, have their own routines carried out and their needs met in a timely manner. Independence was not always mentioned in isolation and for some the loss of it not mentioned as a source of frustration.

6.2(b) Relatives’ views

Relatives had mixed views on what constituted rehabilitation and what approach should be taken. These views are presented in the tensions section, Chapter 11.

Stimulation and Activity

Residents regularly made reference to the necessity of either themselves or others being 'engaged'. Relatives considered the level of stimulation residents received and their opportunities for interest and engagement to be extremely important.

7.1 Engagement

7.1(a) Residents' views

Residents perceived that being 'engaged' could be achieved through trips out, in-house activities and being enabled to carry out normal every day activities.

'...you have to have a reason to get up and get out of bed, everyone has to have something to look forward to don't they, like most people work Monday to Friday and they have their weekend treat to sustain them through the week.' (FG2, Erica)

The importance of having access to shops was highlighted, as was getting out regularly and for some, to be able to visit home.

'[at the Neuro Centre] you can go to the shops, you can go to the pub for dinner or you can just, you could go and sit out on the decking.'

Music was an important aspect of life mentioned by some residents, with three stressing the importance of the quality of music. This was mentioned each time with reference to classical music.

'Music is very important to life. Music is very, very good to giving people an aim in life, it can really uplift the soul and that's really, really important isn't it [and] [playing a musical instrument] that's really important therapy to me.' (INT6, Sarah)

Music is often listened to in the lounge areas, in residents' own rooms, in the gym and enjoyed by residents. Of course, not everyone loves all kinds of music, residents recognise this also *'How do you decide what music is, I might not want what the person [...] next door wants.'* (INT1, Marjorie)

Entertainment in the form of TV or in-house entertainment was not often raised as important. However for two people television was highlighted as being crucial, either for keeping up with the news and for personal entertainment or for their family.

'I think they [TV and DVD player] were pretty crucial not only for the kids but for myself as well.'

Food, the physical taste and the part it plays in socialising was raised as important by residents. The type and choice of food available and the presentation was also mentioned as being important.

'I think the first meal I had here was sausage and mash with onion gravy and it was just, it was just three Michelin star food, it was brilliant, fantastic, hot coffee on tap when you wanted it and ice cold water when you wanted it.' (INT8, Max)

'...it is always sort of sticky when it's pureed and it's better when it comes on a plate rather than dolloped in a bowl.' (FG1, Jean)

'It would be nice to have a cooked breakfast now and again.' (FG2, Arthur)

Being able to smoke was considered important by two residents. One resident discussed how smoking was a significant part of their daily routine and how important it was for staff to be aware of this in order to assist them. The other commented on how much they enjoyed smoking and how, through smoking, they had formed a friendship with another resident.

The input made by the activity co-ordinators on all sites was valued by residents. Comments included how important the co-ordinators' focus of asking residents what they wanted to do and how this could be achieved was appreciated. Erica commented:

'...literally her [activity co-ordinator] first day in the job, it was, "How can I make your lives better, where do you want to go?"' (FG2, Erica)

7.1(b) Relatives' views

Relatives considered the importance of engagement that residents receive from staff and those around them on a day-to-day basis. Relatives emphasised in particular how activities and having a sense of 'community' was key.

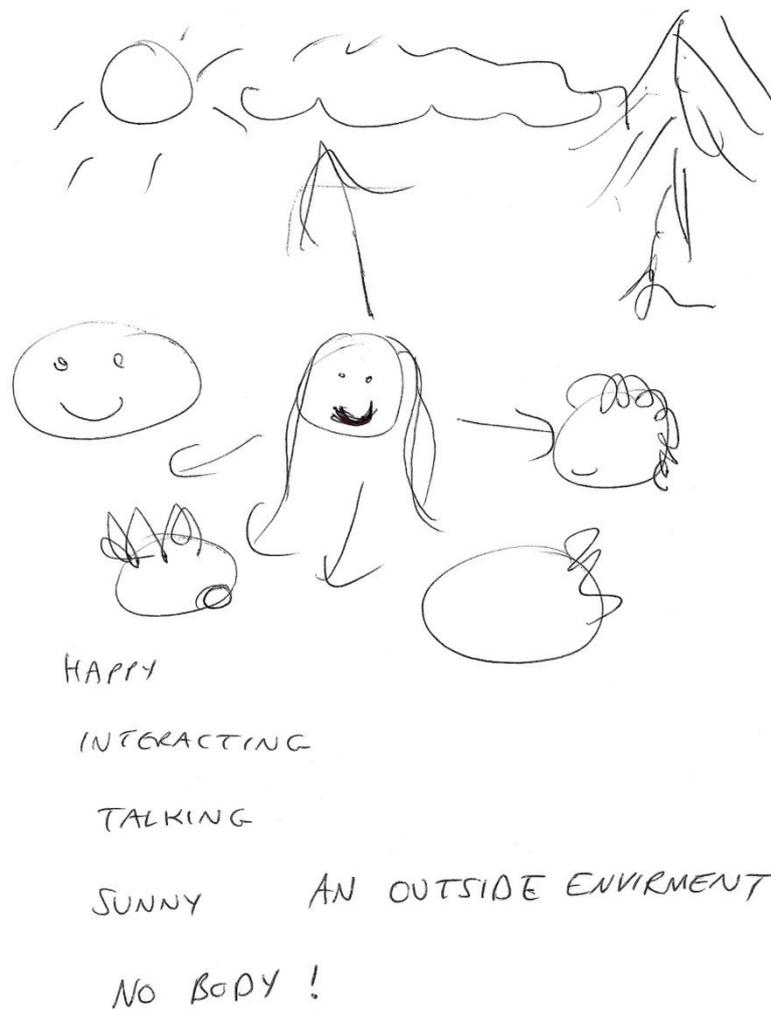
'I think activities for them is really, really important because again, it's stimulation isn't it. It's something towards a normal life because we would go out to things and have entertainment.' (RTFG1, Elaine)

'They're [staff] not just buzzing around, they're interacting with each other so I see that as quite different to other places that I've been to where there's lots of people around, [...] but there is no real community. [...] to me the word 'community' [...] and about communing and actually that is often missing and what you get is a lot of people jostling round in the same place.' (RTFG2, Lois)

Relatives recognised potential barriers to facilitating interaction in long-term care facilities and identified what they felt could happen should residents not have the appropriate level of stimulation.

'I know I get affected when I don't get out and about enough. He was noticeably depressed last autumn [...] He never was one for being stuck in bed.' (RTINT5, Diana)

Illustration 5: A relative's picture of 'good care'.



Relatives feel that socialising and appropriate interactions with others is vital for their loved ones and, for example, talked about the benefits of residents eating together socially.

'They have persuaded him to go to have his meals in the dining room and also we've noticed [...] that he talks to a lot of people and they talk to him and so he is beginning to socialise. We know the type of person he is underneath. He loved people, he loved company.'

They commented on how much they felt residents benefitted from group activities and several felt that activities should take higher priority.

'I think [activity co-ordinator] has been really, really very good. This year so far we've had several concerts, singers and musicians in and I think that is really good. [...] They are very generous when they put events on [...] they've done trips on the canal boat [...] and that is really nice.' (RTFG1, Fran)

'They're not proactive about getting people to the lounge on time if there is going to be some music. [...] they should have been thinking about that an hour before but it doesn't happen and [...] it seems that [the activity co-ordinator] does everything and that seems a bit much and I would have thought that there could be more emphasis on that.' (RTINT5, Diana)

More specifically, relatives raised the importance of in-house activities being meaningful and age appropriate.

'The staff are trying their hardest to do things that are appropriate and make life fun for Luke.' (RTFG1, Fran)

'She [activity coordinator] doesn't seem to do things to suit younger people. No, they're, they're not suitable, she more so arranges things for people with a limited mental capacity to amuse them rather than the mentally capable.' (RTPINT1, Ellen)

Many relatives considered getting out-of-doors or out of the centre as being really important too. This included getting outside for some fresh air, going on a trip out of the centre, going home, or on a proper holiday. *'I'd like to take her away for a week.'* (RTINT6, Barry). They often stressed the importance of going out as being 'normal'.

'I think going out from here is very important. Life and normality [...] even for her to have gone out to the arboretum was phenomenal.'

One focus group participant commented on how important it was that her loved one, although in a state of disordered consciousness, was exposed to different kinds of stimulation and activity. This was not just for the sake of the resident, but so that the relative could talk about her in a way which was helpful for the family, and the message this sent:

'There is something about communicating to the family that yeah they [staff] are trying to make life here as normal as possible [...] I'm the bridge between her and the family [...] she's not just bed bound and seen as a bit of baggage.' (RTFG2, Lois)

Security

Safety and security meant different things to those participating. For some, security was an extremely important factor and for several relatives in particular, it was considered a core element of good care.

8.1 Considerations of safety

8.1(a) Residents' views

The importance of feeling safe was not raised explicitly by residents but a feeling of safety and other elements such as the security of personal possessions and the security of the building were mentioned. Tensions regarding security and freedom was debated and is reported in the tensions section, Chapter 11.

No residents reported feeling 'unsafe' but the exchanges below raise how a sense of safety can be disrupted and influenced by factors that may not necessarily be normally considered as threatening.

INT: *Do you like it if it's quieter or if it's a bit busier?*

Resident: *Quieter.*

INT: *And how do you feel when it's busy?*

Resident: *Threatened.*

INT: *Threatened?*

Resident: *I object to noise. I've got one or two noisy neighbours.*

INT: *How does that affect you?*

Resident: *I object to it. I feel threatened, I can't concentrate. (INT2, Jack)*

Several residents identified the importance of their personal possessions being looked after and handled appropriately.

'...she [carer] tidies my room for me [...] she splits everything up and leaves it immaculate, she takes all the stuff out of my wardrobe and drawers and she'll hang all my clothes up.'
(INT7, Denise)

Arthur discussed his annoyance when his room was reorganised, albeit for practical health care reasons and items moved without his knowledge.

'Well, my room's been rearranged and I can get round in the wheelchair a bit but I still find it frustrating though, things moved when I don't want them to be moved. I like to have things in certain positions and you just find the room isn't big enough or somebody's moved, moved the stuff without telling you.' (FG2, Arthur)

Residents also discussed access in and out of the building. Their sense of freedom was threatened by the coded access in and out of the centre and the reliance residents had on staff to operate the doors. Residents recognised, however, that in this particular instance the current security arrangements were required for the security of others within the setting. All the same:

'You feel very much at times that you are a prisoner.' (FG2, Arthur)

8.1(b) Relatives' views

Relatives raised the issues of security within a long-term care setting. These included risks from other residents and the safeguarding and care of possessions.

'They're good on security which the hospital were lousy at [...] they know who is in the building and they know what sort of people those people are, [...] they make a point of interacting not just with the patients but with the relatives and that's a very important part of protecting and care for the patient.' (RTINT3, Grace)

'...odd residents here that wander about. They can't help it but they just wander into Leo's room. He doesn't like it. They don't know they are doing it but it's, that's the worst thing here.' (RTPINT1, Ellen)

Illustration 6: A relative's picture of 'bad care'.



This relative explained that this picture depicts 'the wanderer' – a resident walking into their loved ones' room unsupervised.

Connectedness and Information

This theme represents the danger of residents becoming isolated, 'cut off', and the need for residents to be connected with the people around them (staff, family and friends), to the immediate community and wider world.

9.1 Connectedness

9.1(a) Residents' views

Residents emphasised that remaining in contact with their lives prior to admission including the local community and their place in the wider world was important and, in some instances, crucial. Residents highlighted their need for socialising with others, keeping up with the local and national news, discussing current affairs through the attendance of 'news groups' and holding 'normal' conversations with other residents, relatives and staff.

'But it [talking with staff] was just, in a way it was your connection with the outside world because these people were doing what I used to do, I used to get up and go to work.' (INT8, Max)

9.1(b) Relatives' views

Families emphasised the importance of their loved one retaining, if possible, a link to the outside world and hoped that visits from family and friends could help the person to feel connected to the wider world. Judy commented:

'She is restricted to people who are there [...] us visitors who are visiting might widen her world a bit.' (RTINT2, Judy)

Relatives discussed the importance of relationships their loved one's held with people other than themselves and spoke of whether or not old friends had stayed in touch (an issue not raised by residents).

'When he first came here he got lots of visitors then, now that time has gone on he hardly gets any friends...' (RTPINT1, Ellen)

The importance of this was reinforced by Elizabeth who had experienced the continuation of a strong and supportive social network.

I've lived in our village since I was young [...] a lot of friends and networks and the local company were brilliant [when loved one went into hospital and subsequently long-term care] they'd missed, Peter was a major lynch pin and they'd missed Peter as much as me and to be truthful they do still. Peter came home last summer [...] and all the mates popped home for the day, it was brilliant.' (RTFG2, Elizabeth)

9.2 The importance of information

9.2(a) Residents' views

Residents not only identified that maintaining connection to the wider world and sharing with each other in a social sense was important but also saw appropriate internal communication as crucial. For example, information being handed over appropriately was highlighted as key. Erica commented:

'If you've got any problems here it's difficult to find who to go to, like in my last hospital you used to have a co-ordinator [...] Inter communication was spot on. Whereas things happen here and I don't think it always gets handed round' (FG2, Erica)

Several residents also raised the importance of receiving timely, correct and accurate information and the way this was approached or delivered.

'Yes. When I first came here the, I, physio was very good and came to see me but nothing else seemed to happen. I was told afterwards that they like a couple of weeks for you to settle in, but it would have been nice to have known that.' (FG1, Jean)

'I don't like to be fobbed off, or told different things.' (INT4, Donna)

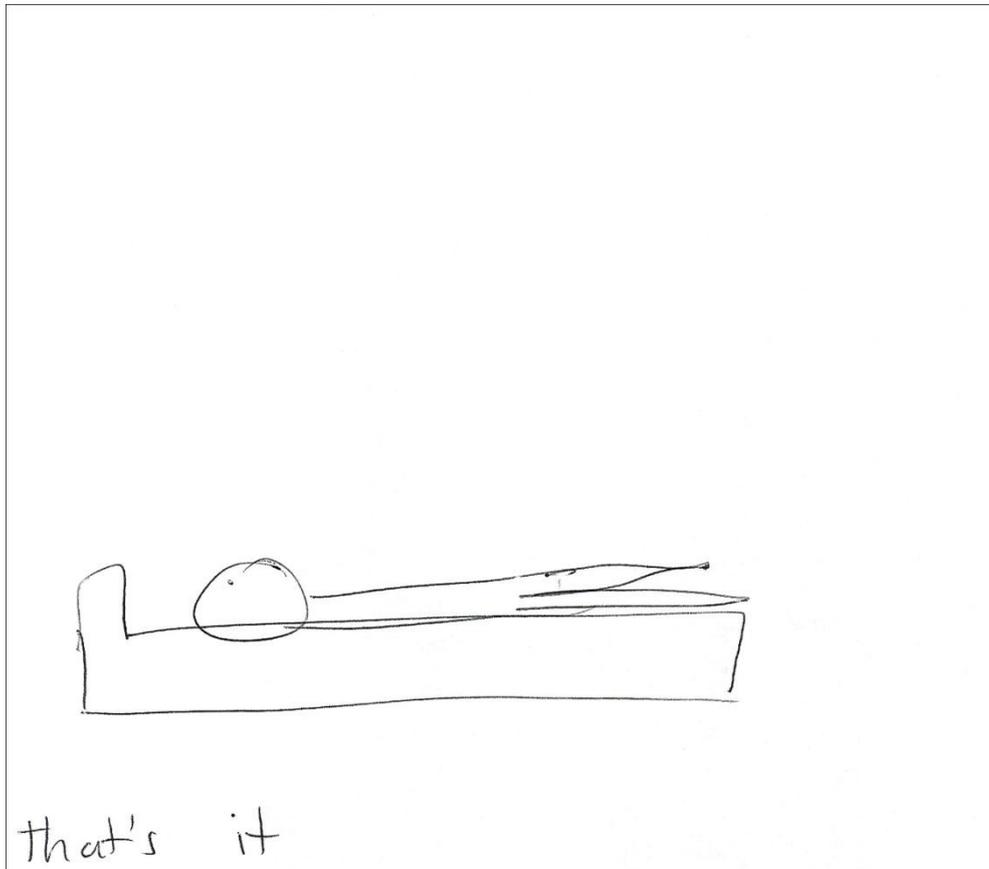
For those for whom communication is difficult, having staff who know them, their needs and their individual routine was identified as being crucial, and having staff who demonstrate that they are making a particular effort to communicate and facilitate communication was also identified as being extremely important.

9.2(b) Relatives' views

Relatives did not discuss the importance of internal information and communication for residents but highlighted the importance of independent communication as a key aspect of this.

'What they have done is got a sort of computer communication aid [...] because he was a great communicator and [...] he needs to communicate, it's an important part of his life. He was always discussing things with people.'

Illustration 7: A relative's picture of 'bad care':



For this relative isolation and lack of stimulation was a feature of 'bad care'.

Environment

The importance of environment was significant to both residents and relatives. Residents highlighted the importance of 'a good environment to live in', discussing elements such as space, noise, atmosphere and equipment.

As well as considering the physical environment, relatives placed greater emphasis on the importance of atmosphere, considering homeliness and what constitutes home, and also identified facilities and access to the centre as important.

10.1 Physical environment

10.1(a) Residents' views

'I think it's fantastic architecture. I love architecture. They've built this fantastically haven't they [...] I think it's beautiful and [...] very spacious.'

Space within the centre was repeatedly highlighted, in reference to residents' rooms in particular. Residents who discussed their rooms considered whether it was good or bad in reference to its size and/or its position within the building. The space in corridors and bathrooms were also raised. Space was also discussed in reference to architecture, how the space was planned and whether it looked nice or not.

Space was discussed with reference to its impact on socialising. Having the appropriate space and environment to maintain contact with friends and family and to have quiet space was important for some residents. Max commented:

'...even if we just wanted a bit of quiet, a few afternoons we'd come upstairs and put a DVD on so we were out the way of everyone else but it's just nice to sit and have that family time and its, because it's quite a big building there's, you can sit and talk to other people or you can go and find yourself a quiet corner and just sit down and do what you like.' (INT8, Max)

10.1(b) Relatives' views

'It had been built as a piece of architecture to encourage community.'

'Natural light equals happiness.'

Relatives often highlighted the physical environment of the setting, both for how it affected them and the impact it had on their loved ones. They discussed areas that they thought worked particularly well for themselves and their loved ones and areas that they felt could be improved. Space was something discussed widely and considered to be extremely important for socialising as well as practicality.

'The space at [The Neuro Centre] is well organised for meeting, interacting.' (RTINT3, Grace)

'As soon as we came in, it was all brand new, there was space for wheelchairs to whizz around, where Colin was [at previous placement] it was a little room.' (RTFG2, Carole)

Simon considered an individual room for his family member to be crucial for their privacy. *'Individual room is very important, gives privacy.'* (RTINT1, Simon), and one relative identified the positive effect an individual room had had on their loved one.

'I think when she first came in, having a room on her own, there was something about coming in here that seemed to make her much calmer and more able to concentrate.'

Some relatives felt that the view from their loved ones' room, the internal décor and cleanliness was important *'[The Neuro Centre has] done well with knockers on the door, extra wide doors, cleanliness, garden views.'* (RTINT3, Grace) and for many relatives natural light was deemed especially important.

'...the place needs a paint, it really, really does. It just looks tired [...] really someone should get up there with a paint brush and liven the place up [...] It needs some investment and seems like it's being run at the margins.'

'This was posh. You come in here and it's modern, clean and tidy. [...] Frank had been in [respite centre], nice people but the building [...] light switches hanging off.' (RTFG3, Hilary)

Relatives compared the long-term care setting to their experiences of visiting loved ones within the acute care hospital or other long-term care settings. One critical comment was:

'ITU was so awful [...] he didn't have daylight, there were no windows, no day and night and to come to somewhere like that [neuro centre] where you can get dressed and have a daily routine and see trees and birds is fantastic, it's a step towards normality and was brilliant..' (RTINT5, Diana)

10.2 The importance of a good atmosphere

10.2(a) Residents' views

Residents discussed the atmosphere being different on a week day compared to the weekend and how that affected them:

'I think [The Neuro Centre's] got a different environment at the weekend, [...] I don't necessarily think that's a bad thing. I think, probably makes you appreciate Monday to Friday a bit more because it's obviously buzzing with lots of people but the weekends there is time to chill out.' (FG2, Erica)

Joe remarked:

'There is quite a nice atmosphere here and everyone wants to help you, you can't ask for much more.' (FG1, Joe)

Noise was discussed in both focus groups and in almost all resident interviews. The impact of noise from a range of sources was identified.

'I prefer it quiet. The porters make quite a lot of noise in the morning.' (FG1, Jean)

'I'm fortunate as I've always been down a nice quiet corridor so the only sounds I've got are machines further up that bleep.' (FG2, Erica)

'I don't like people who keep me awake at night.' (INT7, Denise)

10.2(b) Relatives' views

The environment within the centres was discussed repeatedly and at length by many relatives. The importance of home and 'homeliness' was a topic that stimulated much discussion, especially in relatives' focus groups.

'The room Frank was offered was really nice, it felt homely.' (RTFG3, Hilary)

'It is a home from home and I think that's the best thing isn't it [...] the reason I say that, that being in a major hospital, after being in [rehab unit] and another [respite centre] and I didn't like it and he didn't like it.' (RTFG2, Elizabeth)

'They had a Christmas tree up, they had the decorations up [...] and [other family members] just went, they hadn't seen anything, "wow it's like, it's home here." When I use homely, I can't see it home from home but I think for me the word is homely.' (RTFG2, Lois)

One focus group in particular explored what they felt 'home' was and how certain elements of what makes home were or were not being fulfilled within the long-term care setting.

Relative 1: *'No unit can ever be home from home can it [...] [The Neuro Centre] is the best next to home but I wouldn't call it home from home [...]*

INT: *And the ways that this is home from home?*

Relative 2: *This is the best [...] this is so much better [than another unit] so much more relaxed, the staff are approachable, they actually know you, who Peter is, they know his little foibles.'* (RTFG2)

For some families personalisation was key to creating 'home'.

'...he loves bright bedding so we brought bright bedding and pictures.'

'...they are able to bring home into here [...] the words "You can redecorate the room how you want [...] you can do it up as you like, you can redecorate it, you can even have a carpet if you want, you can have whatever on the walls if you want" [...] because you are moving from the hospital environment where everything is so rigid you can't even have your flowers [...]. For me, it's bringing home into here as opposed to saying it's home from home.' (RTFG2, Lois)

Many relatives considered the atmosphere within the care setting to be important. A good atmosphere was generally considered to be somewhere with 'life', 'buzz' and evident interaction. Relatives expressed how all of these things provided a sense of community, which contributed heavily to creating a good atmosphere.

'When you come in you haven't got starchy nurses and hospital smells have you, it's friendly.' (RTFG2, Carole)

Relative 1: *'We ended up looking at [a Rehab Unit] and here [...] the innate quietness there [at the Rehab Unit] [...]*

Relative 2: *No life.*

Relative 1: *No life, correct. [...] we saw one resident in the main lounge and it was a bit, where's everybody else? [...] it was cold [...] there was no life; if there is no life there is nothing to bring life up [...]* (RTFG2)

Many relatives discussed their initial impressions of long-term care settings. The atmosphere and, for some, their first impression was identified to be hugely important when choosing a long-term care setting with their loved one.

'...he is a young person and wants to do things that are appropriate to young people and we actually looked at [an independent health care nursing home], beautiful [...] it had wonderful curtains and carpets but it just wasn't right for Luke, you just felt it as soon as you went in, the age group was wrong, the activities were wrong, as soon as we walked into [the neuro centre] we felt there was a buzz about the place.' (RTFG1, Fran)

'It struck us that there was a buzz about the place and people, they were different levels of disability [...] the fact that there were different age groups, different levels of disability [...] actually, made a huge difference.' (RTFG2, Lois)

The fact that people did not seem to be drugged to keep them quiet was highlighted:

'You don't get them where they seem to be doped up to keep the peace [...] they actually try to keep them on the minimum for what they require rather than, sometimes you get the impression that they are walking zombies [at other units relatives had experienced in the past].' (RTFG2, Elizabeth)

Several relatives discussed the requirement for an understanding of spirituality and the importance of how it was incorporated in understanding the individual and embodied in the atmosphere and environment of the centre as important.

Relative 1: *'...when I was looking around I asked myself can that spiritual side, whatever that means to Sally and to us actually coexist and exist when actually nobody verbalises it [...] The spirit of place and the spirit of person [...] our connection however you like to give that.'*

Relative 2: *'There is a warmth to the place that you don't find with others. [...] I think most people who have been through any kind of life changing situation find some form of spirituality even if it's just realising that a lot of things we thought were important, aren't.'* (RTFG2)

10.3 Equipment, Facilities and Services

10.3(a) Residents' views

Lastly residents discussed equipment and facilities. This tended to be discussed as a form of comparison to either other parts of the same centre or different care institutions.

'Half the bathrooms have, I don't know might be more, have, they've all got en-suite bathrooms don't they but some of them have huge showers, some of them just have a sink and a toilet. So, um I'm thinking it would have been better if they'd done every room.' (FG2, Erica)

The environment clearly has its part to play; having enough space and the level of noise are the factors most effecting residents within this theme.

10.3(b) Relatives' views

For some relatives the facilities available were important not only for their loved ones, but for themselves. One joked:

'...you could get free cups of coffee! Never mind Pippa, I could get a free cup of coffee!'

Three relatives in another focus group also similarly commented on the importance of access to refreshments for their loved ones and themselves.

Relative 1: *'I'll come in and say well Peter are you going to sort out a cup of coffee, because he can so rather than sitting there [...] and it just gives you that [...] it may sound really stupid.'*

Relative 2: *'It's not [...] and actually you can help yourself and there is a freedom to, I think that makes a big difference. [...]*

Relative 3: *'[...] because there is something so artificial visiting with people and being in a room, especially if they have energy levels that go up and down or they need time out, being able to fluidly move around the building as a visitor and as a family.'* (RTFG2)

Facilities such as televisions *'They've got great tellies here. I think Frank looks very comfortable when he is watching television in his room.'* (RTFG3, Hilary) and comfortable seating *'To have a few decent chairs, somewhere you could sit comfortably [...] the lounges aren't comfortable.'* (RTINT5, Diana) were deemed important to relatives.

Location, free parking and access to local amenities were also important. As one relative commented:

'It is nice that you can just drive the electric wheelchair around the corner and have a pub lunch.'

Both catering and laundry services were also discussed. Several relatives identified how looking after their loved one's clothes was valued as part of maintaining their loved one's dignity and was a sign of the service paying attention to detail. Several discussed food, reporting that food choice, variety and healthy eating options were important.

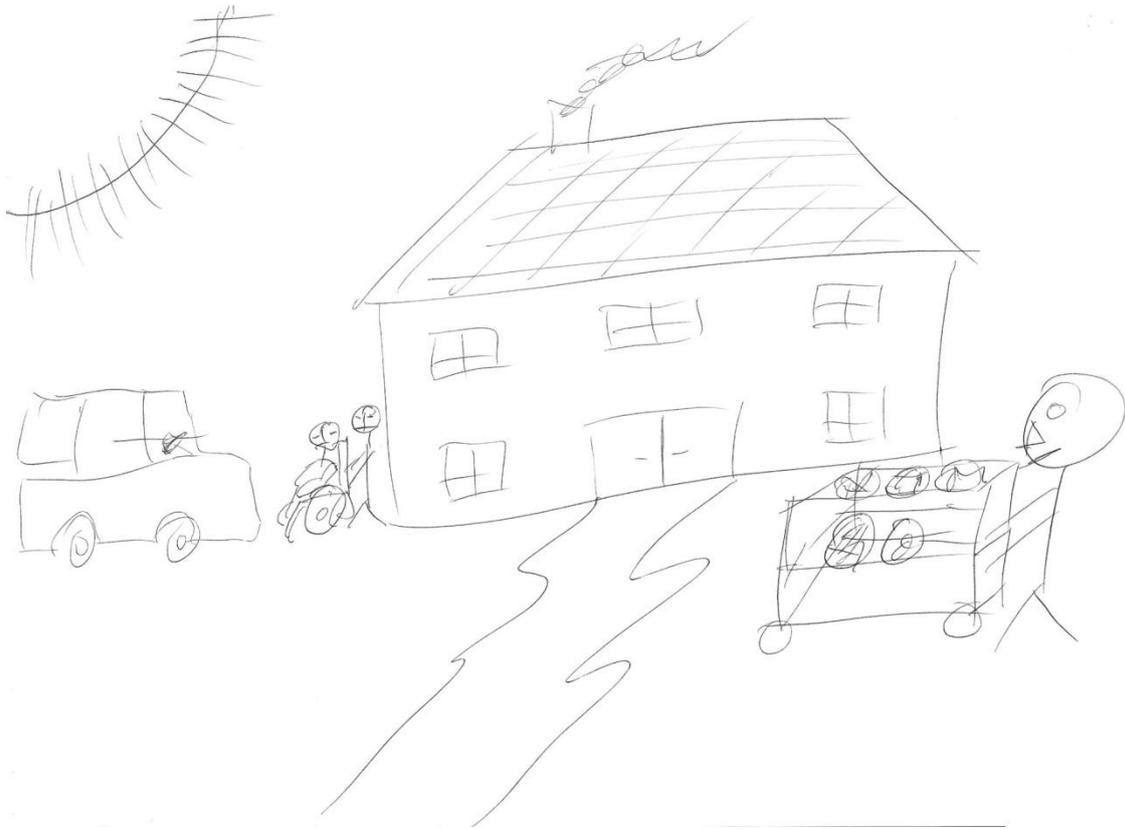
'Like most institutions they have lasagne and chips [...] the catering staff are very good.' (RTFG1, Elaine)

'We've battled with food [...] the menu hadn't changed for months on end [...], They were going month in month out with loads of things people didn't like. [...] So we had a meeting [...] and they've put out a new menu which looks a bit better.' (RTPINT1, Martin)

Both residents and relatives mentioned one key area that they felt was missing at one of the centres.

'It's the one thing that's missing here [Kitchen] and actually that might create more community because that's where you bump into people.' (RTFG2, Lois)

Illustration 7: A relative's drawing of 'good care'.



Food – the variety, quality and presentation of food is important as are social occasions where food is enjoyed together

Balancing Tensions

Certain topics generated significant self-reflection in interviews and/or debates in the focus groups. During discussion, residents and relatives often supported one another and expressed strong agreement but they also challenged each other's views, and through these conversations a series of tensions or 'balancing acts' emerged. Some of these tensions have been highlighted in the preceding chapters, for example the tension that residents manage between wanting staff to be 'friendly' or even 'friends', and wanting them to be professional has been explored in chapter 4. In this chapter we draw out three key tensions that also emerged from the data.

Although these tensions may not be indicative of what is important, they are an extension of the themes identified in Chapters 4-10 and such debate does provide significant insight into issues faced.

11.1 Risk taking and independence versus security

11.1(a) Residents' debate

The topic of going out on trips to the pub unaccompanied was discussed and evolved into a debate regarding risk taking to achieve independence versus their own personal safety. One resident felt annoyed that he was discouraged to go to the pub without accompaniment. However, as the conversation developed, they considered why they had received such discouragement and began to reference their own personal safety.

Resident 1: It seems unfair if your brains working ok and you can get around in one of these [electric wheelchair], the rules still apply that 'oh you can't go and do these things.' In a sense it's a, a backwards step [...] because when you go back to your own home, you've got to have the confidence to do things.

Resident 2: I can totally see where you are coming from Gordon because you are obviously a middle aged man, you're independent, you've lived your whole life, if you want to go to the pub you go, you don't have to ask permission.

Resident 1: That's right [...] until you come into this environment.

Resident 2: It's so easy for something to happen. When I went to the pub the other day, the wheel got stuck and I couldn't get out, until someone lifted the chair. It's so easy to, anything can happen to us so I can understand that they want to keep us safe.

Resident 1: *So I could be a bit cavalier about it.*

Resident 2: *Yeah [laughs]*

Resident 1: *In a sense. That's been my tendency during my life. Yeah, a bit cavalier.*

As highlighted above, independence is important to residents and being able to go out and access normal every day activities forms a large part of this. The debate above would suggest that residents need to exercise their right to take their own risks as they were able to prior to their injuries ('That's been my tendency during my life. Yeah, a bit cavalier'). However, considering how on reflection the resident's drive for risk is reduced, maybe the real challenge they face is achieving a balance of how to assert their independence without endangering themselves more than they want to. It may, therefore, be that the important element for residents in long-term care facilities is that the staff working with them demonstrate their understanding of this on-going conflict and make every effort to assist them achieve a balance that works for them in their everyday life, rather than imposing a 'risk reduction' strategy on them.

11.1(b) Relatives' debate

A tension that was apparent in several focus groups and interviews with relatives concerned the balance of rehabilitation. Some relatives were of the opinion that their loved one should be 'pushed' as much as possible in order to maximise recovery, others felt quite the opposite. Thus, for example, some relatives made comments such as:

'More intensive treatment for Patricia. She definitely could have stood it. [...] It could have been pushed a lot harder that it was.' (RTINT4, Ray)

'The physio, I understand that it has to be slow and gentle but at the moment I feel he needs more.' (RTINT5, Diana)

Relative 1: *'...it's a brilliant unit [...] but I think they don't/can't push the way I feel they should push.'*

Relative 2: *'When Colin first came in he couldn't speak or anything so they took him to physio and he had physio but then when he started to talk and they take him to physio and he says no, they can't make him, but before he could talk you made him.'*

Others highlighted the 'difference between stretch and push'.

Relative: *'The therapy for us is critical. [...] she's getting probably as much as she did at [the rehabilitation hospital], it's not demanded of her in quite the same fashion I think because when you're intensive, this is your time, this is your hour...'*

INT: *So for you, it's not demanded of her, is that a good or a bad thing?*

Relative: *[...] it's the way in which people, she's asked. I believe in her being stretched and asked to do it, there's a difference in that and 'Come on move that arm up, move that arm up, move that arm up, move that arm up' [...] there is a difference between stretch and push.'* (RTFG2)

Sometimes different views lead to debates within focus groups.

Relative 1: *'Some people respond differently in the fact that some people might think if I don't have to be bothered, I won't bother thank you very much and they need to be pushed [...] It's knowing the level of the person and knowing where they are at physically and mentally and emotionally as to whether you do push or you don't push [...]*

Relative 2: *And the carer will say well he wanted a lie-in this morning, well that's not on.*

Relative 1: *I do struggle with that one [...]*

Relative 3: *The challenge I give back to you is who says its wrong? [...] what judgement are we putting on that in terms of our normal way of living, mine, yours, whoever's, you know, you get up at whatever time, that's when you should be getting up. Is that's what's needed? There's perhaps a balancing act there, how do you get that balance? (RTFG2)*

11.2 Routine versus Institutionalisation

11.2(a) Residents' views

Much discussion arose in resident focus groups regarding the limitations of institutionalised living. This generated tensions including freedom versus security and the comfort of routine versus the risk of becoming 'institutionalised'. Residents debated issues they faced regarding the times that they got up and went to bed and the pros and cons of routine.

Residents debated how obsessing over routine could contribute to them becoming institutionalised.

'I think routine, I don't know, sometimes you can get a bit obsessive [...] with myself, once you start it, it sort of becomes your life and then, I think it's good to break out of the mould sometimes and change it up...'

Although no consensus was reached, what seemed to be deemed most important was to have the availability of staff to provide both the set routine required *and* to allow flexibility.

11.2(b) Relatives' views

Relatives, like residents, considered the pros and cons of a strict routine within the long-term setting.

'The danger for Sally, even here, is that there is a regime and she gets caught up in the regime. Now the regime says uh you sleep, you turn, you've got four hours in the wheel chair da da da da and I'm saying to people, I know we need to build her up in the wheelchair I quite agree with that [...] can we move away or try and break your notion of a routine up and would it be better for her and only Sally will answer that' (RTFG2, Lois)

11.3 Individual versus collective needs

11.3(a) Residents' views

The final conflict discussed here is perhaps the most difficult and most thought provoking. As seen above, residents discussed their requirement for their particular needs to be met. Here, however, they identify the problem when the meeting of their needs is in direct conflict with the needs and, more crucially, the rights of others.

Many resident participants identify noise levels to be an issue. Here this issue is opened up to consider the rights of the individual versus equality.

Resident A: I think it opens up an interesting debate around segregation and whether all these people are right to be mixed into one place.

Residents B: Why not put all the noisy ones together?

Resident A: But again, I don't, don't, if that's discriminating against, I don't know, if you put say all the screamers and shouters down one corridor they're all disturbing each other but then there are people that are quiet that don't want the screamers and the shouters. I've heard some families say "oh it's not right you, you people being amongst people like that", like 'that', as if people with a head injury shouldn't be looked at, as if it's so monstrous to see them, like we should be shielded and protected from looking at that. We shouldn't have to hear people shouting all day but then...

Resident B: When you've got something like MS you need some peace and quiet at night otherwise it doesn't do you any good.'

Throughout data collection, residents consider the importance of their relationship with each other from the fun of socialising, the sense of camaraderie and the positive impact of being around others who face similar challenges, in order to learn from each other or to become more comfortable with a particular impairment. They face, however, the reality that is the challenge of meeting the very diverse needs of each individual without negatively impacting on another.

Residents recognise that achieving this is difficult but the answer lies in creating a balance.

'It's getting the balance; each patient has the same rights.'

11.3(b) Relatives' views

Similarly to residents, relatives also considered the pros and cons of residents with mixed levels of disabilities living together in long-term care settings.

Relative 1: *'That's the difference for me between here and [another rehabilitation unit] because [the other unit] is really clear, they have different units set up according to the level of your rehabilitation [...]*

INT: *And what are the pros and cons of that, that we have a much more mixed community here?*

Relative 2: *I think it's good otherwise you could become institutionalised, like you were saying, at never progressing because you are boxed as being 'that' person [...]if you went into that unit and you had hope but everyone in that unit were cabbages then you would be suicidal as a family but if you, when I went into [Neuro rehabilitation hospital] [...] you saw some that were starting to brush their teeth and sort themselves out you have more hope so I think to have it segregational for me wouldn't work.'* (RTFG2)

These discussions and reflections demonstrate the range of inherent tensions in which residents are faced with, and those considered by relatives. Institutionalised living and a patient pathway leading to institutional placement of any sort will undoubtedly be the source of a variety of tensions. The identification of some of these tensions raise wider issues that may not necessarily be able to be solved, but should at the very least be engaged with and discussed openly between provider and user in order to either recognise and promote an environment of understanding or take action to resolve or improve them.

Relatives' Needs and Concerns

Aside from the data relatives gave us detailing what they felt was most important for residents, relatives also identified some additional key issues that were important to them and these are summarised in this chapter.

12.1 Financial and Care security

Securing the future for their loved one was evidently of significant concern and many relatives raised concerns about the welfare of their loved one in the event of their own death or injury. Relatives explained the preparations they had either made already or needed to make.

'We were looking after Selene for twenty four hours a day [...] as we are getting older it's getting progressively more difficult [...] age creeps up on you and we do realise even if we manage to keep our heads above ground, our ability to cope is getting worse [...] Because it could be in the not so distant future someone is doing it for me. That is what drives us forward, we know we don't have a choice, we have to get things sorted for some long-term care for Selene.' (RTFG3, Geoff)

'We did all ours [legal arrangements] before Frank came ill. It was sorted as soon as we found out that Frank's mother had the disease. I'm his Power of Attorney and if it's not me it's my children.' (RTFG3, Hilary)

Relatives also discussed how the uncertainty of on-going funding affected them.

'The problem I have [...] it's this every six weeks being reviewed and not knowing [...] will they continue funding or not [...] to think, if I had [a bout of serious illness] [...] I just want to know that I have him settled somewhere. [...] I'm quite happy with the care and everything he is getting but there is always that what is going to happen in June?' (RTFG1, Elaine)

'We haven't personalised her room in anyway because we've got this threat all the time that we're going to be moving out. It's a constant worry.' (RTFG3, Maggie)

One focus group also discussed the potential impact of government changes to strategy.

'What I worry is this wholesale colossal change in the structure of the NHS doing away with the primary care trusts and replacing by a consortia of GPs, now these GPs are going to have their own agenda and I fear that neurological disorders [...] are going to be very low on their priority list.' (RTFG3, Geoff)

12.2 Relatives' relationship with staff and their role in the care team

Relatives discussed how strong relationships with staff led to improved communication and security and expressed how being known by staff helped them personally to feel welcomed and part of the centre's community.

'The ones [staff] who know me do [acknowledge relative when she visits] actually yeah [...] because I had a long period of not visiting I felt really out of it and one person remembered "Hi Judy how are you?" and yes, that's nice, it makes you feel more like coming back because you feel part of it.' (RTINT2, Judy)

Alongside this, relatives explained how staff acknowledging and respecting the importance of their role in caring for their loved one and being willing to learn with and from them assisted relatives to feel part of a team of people caring for their loved one, another key aspect for them.

'I feel that the staff have the same aims as me to get her pad changed as soon as possible, they might not be able to do it and I might not understand always why they can't then but they do have the same aim in mind. So we are on the same team whereas in a hospital you are the opposite team, you know I want my sister changed and they want to do their paperwork. I've never seen paperwork take priority at [The Neuro Centre].' (RTINT3, Grace)

Relatives raised their own need to learn and develop skills and talked about how this enabled them to operate more effectively as part of the team supporting their loved one

'I would have liked to have been there when she was doing some of her occupational therapy or physiotherapy, it would have been very useful for me to see that because I could have probably learned a lot from it.' (RTINT4, Ray)

and discussed how having strong relationships with staff enabled them to have disputes and disagreements that did not negatively affect their day-to-day relationship with staff.

'I have snapped at staff occasionally and I really appreciate this, they know I'm under stress, they're under stress in fact and I know they're under stress but when I come in a few days later its fine, we've started, "Hi how are you" [...] they don't hold grudges.' (RTINT3, Grace)

Staff continuity was identified as having a significant impact on them and the care of their loved one and, like residents, also demonstrated genuine consideration for staff caring for their loved ones.

'The whole of the staff were so demoralised it was untrue. [...] They were still looking after patients and the people but you can see it was really hard work them trying to do the job [...] Personally I couldn't do it, I couldn't even do it for more money. And I don't know how they do it for the money they do and I do feel sorry for them in that respect because they do a lot of work.'

The importance of access to information was detailed as extremely important. Relatives wanted to be kept informed about a range of issues including:

- *their loved one's condition:*

'The main thing here that I find fantastic is respect, courtesy from staff, being informed about what is going on progressively in her condition, always being proactive in telling us so we're not shocked and thinking gosh she isn't doing this anymore or whatever [...] we are really happy here, it's a really good place.' (RTFG1, Portia)

- *facilities and options:*

Relative 1: *'The only problem I have with [the neuro centre] is communication. Keeping you informed. I want to leave enough money to make sure that she can take advantage of everything possible. [...]*

Relative 2: *'I didn't know the hairdresser came into the building [...] Sometimes it's difficult to find out what has been going on [...] I don't want to add to their work load, they must be really quite busy but at the same time as relatives you need to know how your loved ones are doing and if there is anything they need or can we do anything to help or whatever and you can't always find out.'* (RTFG3)

12.3 Relatives' need for information

Relatives valued a thorough induction when their relatives are admitted and specifically noted the importance of welcoming and well-informed staff on reception.

'Having a welcoming receptionist is great. A knowledgeable, welcoming receptionist. Well she knows who is in the building, what days people normally show up, who's busy, who's not.' (RTINT3, Grace)

Accessing information from external services was a repeated 'bone of contention' for many relatives and was a source of much stress and frustration.

'Communication throughout the NHS wherever it is, is dreadful and it seems something sadly lacking. Because they understand the system they don't put it over to anybody else very easily.' (RTINT5, Diana)

By the time families reach long-term care settings, they have often had a series of battles to have their loved one's needs addressed.

Relatives spoke of clinical needs assessments that were ignored:

'Patricia has been assessed by at least three different neuro-psychiatrists, they've all written quite long reports [...] ending with recommendations on what should be done and they are all written to our GP or the PCT people like that and no one took a blind bit of notice.' (RTINT4, Ray)

They described empty promises and the struggle to access rehabilitation services, mistakes and inefficiency in supplying equipment, *'...like the initial wheelchair was meant to be electric, turned up manual.'* (RTPINT1, Martin), failures in co-ordination and difficulties accessing information:

'I call them un-help lines - they are designed to keep you away from the person who knows what they're doing.' (RTFG3, Maggie)

They were also often embroiled in problems sorting out their loved ones finances, or trying to deal with funding issues:

'Fighting to just get through the financial stuff, we don't need this on top of everything else. The enormous well sadness of it all, you're dealing with, you didn't want this, you didn't want it for them and they would be horrified I'm sure if they knew they were going to end up like this and on top of everything there is all this bureaucracy.' (RTFG3, Maggie)

Such issues contributed to relatives feeling isolated, unsupported and angered by the various health and social systems they have encountered before reaching long-term care.

Relative 1: *'I can't pick faults in [the neuro centre] as to what we need for us because my problems weren't here, they were the incompetence and the lack of support from Social Services and the rehab hospitals that you go to that deal with it every day but made me feel as if I was a total one-off, that's the ones I really have issues with.'*

Relative 2: *By the time we get to [long-term care] a lot of the issues or fights we've had have been resolved. [...] what needs to exist before that is really practical help support hand holding, the 'how' to, the 'who' to [...] how do you fight your corner [...]'* (RTFG2)

Relatives also talked about how they were struggling with trying to get the information and services that were needed.

'Having a relative in that state is such a shock to the system [...] you are all groping at what you are supposed to do, how you understand what you are told, what decisions you can and can't make, I mean it's just a totally unknown world.' (RTINT3, Grace)

They described feeling over-stretched and torn between caring for different family members (especially children or elderly parents).

'I didn't give [daughter] the support I should have done because I was up at the hospital [with the father] [...] what I'd love to say to a parent in my position, "Think, think about the rest of the family as well." It's very difficult to chop yourself in half.' (RTFG1, Elaine)

Relatives also spoke about their grief:

'You're not dealing with death but you are dealing with a kind of death.' (RTINT2, Judy)

12.4 Medical Decision Making

Medical decision making was often highlighted as an area of concern within the focus groups and interviews with relatives. Although not often thought of as a 'long-term care provision' issue, the views expressed about this came across powerfully and form part of relatives' experiences of long-term care.

Relatives frequently expressed their need for regular and accurate medical information, and described how difficult they found it at times to access such information.

'I asked them for a copy what was sent to the doctor and I haven't had it and I think I should have one because I look after her. [...] I want to know all the facts, my son is the next one, should anything happen to me so it's obvious he should know. She's life to us and we've got to know the attention she needs and things like that and some doctors could be wrong.' (RTINT6, Barry)

'...the one huge problem that we have always had is patient confidentiality and it has been used, in my opinion as an excuse by medics for doing nothing and they can hide behind this patient confidentiality [...], it makes it very, very difficult for carers and relatives [...] we have found this to be a tremendous hurdle and with the medical people saying [...], "We can't discuss this with you, we've got to discuss it with Selene", but Selene won't discuss it with you!' (RTFG3, Geoff)

and discussed their experiences of how medical information is communicated.

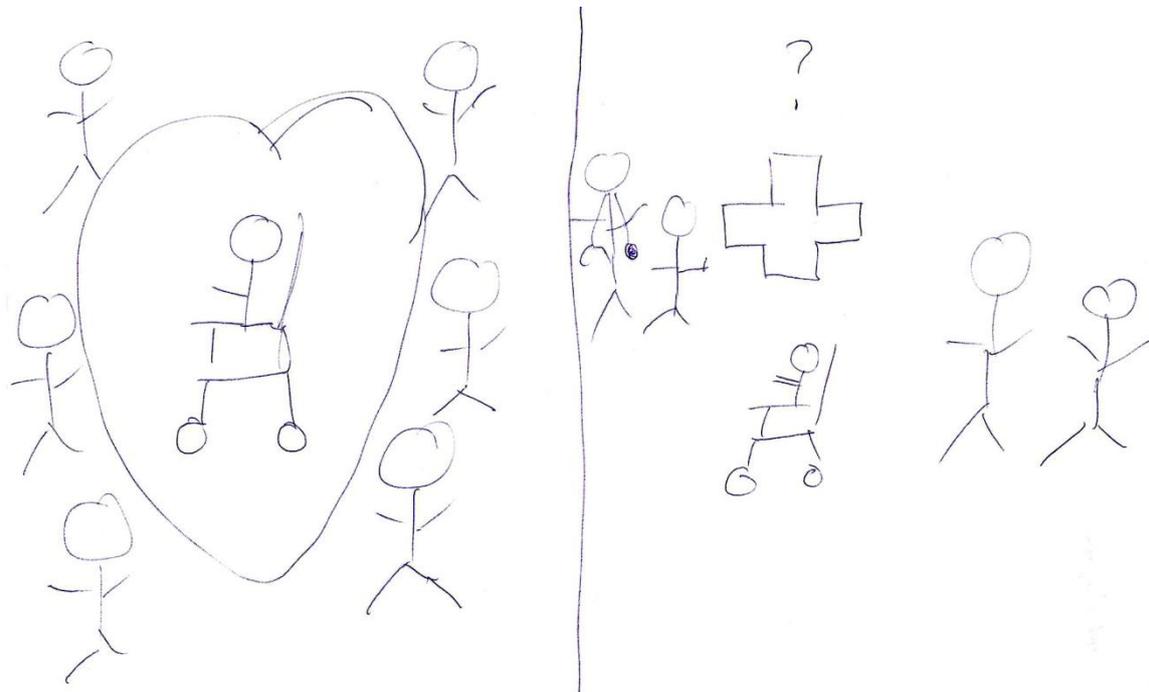
'We weren't even told that Selene was on medication at one point or that it had been changed. [...] But then they put her on an antipsychotic drug [...] It wasn't until I actually looked it up and found out that it's for treatment of [X] [...] but no one had actually told us. [...] It would be nice to be informed or consulted. I don't want her to be pumped full of all sorts [...] I just felt we had the right to know.' (RTFG3, Geoff)

They wanted medical treatments discussed with them, explained to them, and commented that if this was not done by the professionals then they would pursue their own (not necessarily helpful) alternatives:

'There's not always someone to explain it and the worst scenario is you go and look on the Internet [...] because you'll always find the bad one. You don't read the good stuff, "oh no, oh no", you start worrying'. (RTPINT1, Martin)

'I would like them to write things down. So, for instance, [the doctor could write] I have changed [her] medication from A to B because on such and such a date and will be reviewed on such and such a date.' (RTINT3, Grace)

Illustration 9: A relative's drawing depicting their idea of 'good care' (on the left) and 'bad care' (on the right).



This relative explained that this picture represented how she wanted her daughter to be the centre of a caring team but she sometimes felt excluded from having an input into decisions about her daughter's medical treatment.

Relatives also emphasised how the approach, courtesy and place of communication can make an impact, especially when discussing sensitive topics.

'I would expect a professional person to take me [somewhere private] to speak to me not in the corridor with lots of other people walking up and down distracting you [...] it was just the courtesy so I felt that was poor.' (RTFG1, Elaine)

'...it's the hardest thing to talk about and the last thing you want to have to do is grab a doctor in the corridor.' (RTFG1, Fran)

On the other hand, a thorough and careful discussion was really valued:

'The way they dealt with it [Allow Natural Death Order] you felt you could talk to them, they were sympathetic, they said they want to do the best for [him] and have everything in place, it was positive rather than negative.' (RTFG1, Fran)

Many discussed their involvement (or lack of involvement) in serious medical decisions affecting their loved one, and some expressed concern that their loved one's prior values and beliefs should not be overridden and the challenges as a relative of trying to honour these prior wishes.

Relatives also felt they brought a history of understanding or shared cultural values:

'They do not necessarily understand culture, certainly not her culture [...] it just seems like they are the last people on earth who should be helping her make decisions because they don't understand her.' (RTINT3, Grace)

Relatives who were parents of individuals with neurological conditions felt frustrated with the change in their legal decision making position once their son turned 18.² They wanted a role in helping their loved one make decisions – and did not feel medical professionals were necessarily equipped to do this.

'...we have always taken Luke to all his hospital and doctors' appointments, now he is technically an adult and legally we don't have the right to say, although he is still our son, of what treatment he can have and what he can't. Obviously they involve us but I still find it quite difficult that sometimes [...] we can come in and they'll say "oh they've put him on such and such an antibiotic" for instance, now I used to know them off by heart, what suited him and what didn't, what interacted with his other medication and I find it's difficult to be sort of slightly outside of that loop.' (RTFG1, Fran)

² Parents have a range of legal responsibilities for their child. Parental responsibility is a legal concept that consists of the rights, duties, powers, responsibilities and authority that parents have in respect of their children. It includes the right to give consent to medical treatment. Children under the age of 16 deemed competent can, however, consent to diagnosis and treatment on their own behalf providing they understand the implications. However in England and Wales, no statute governs the rights of people under 16 to give consent to medical treatment, and there remains some uncertainty under common law. (www.bma.org.uk - British Medical Association.)

Despite the information above, the legal age of adulthood in England and Wales 'the age of majority' is 18. (www.hmrc.gov.uk) and in law, it is only at this point that all legal parental responsibility ends.

Relatives discussed their own issues regarding the long-term implications for them and their loved one following medical decisions to extend life, whether they had or had not been involved in these decisions. Looking back at early decision making (e.g. in intensive care), relatives sometimes questioned the value of aggressive life-sustaining interventions:

Relative 1: *'...all you want at the time is for them to live isn't it, you don't think what's, maybe it would have been the better thing [death] at the time, you don't do you.*

Relative 2: *[...] the intensive care woman was saying well [...] really he's not going to have any quality of life, and then you get somebody else saying well actually he should recover to a functional ability to be in the family home, but you hang on to that without realising how destructive having...*

Relative 1: *What goes with it.*

Relative 2: *Yeah the destruction of having twenty four–seven care at home [...]' (RTFG2)*

Some relatives were concerned that their loved one was now enduring such a poor quality of life, that it was not a life they would have chosen to live. For example, in one group of relatives, one member expressed the strong view that her loved one would rather have died, a view with which other members concurred. However, one member of this group explained that she felt very differently:

'I think she has a purpose to be as she is [...] a real purpose, partly for her and partly for others.'

However, others felt that they themselves would not want to be kept alive at 'any cost' (for them or their families) and that care homes could be too geared towards intervention.

'It isn't as important to keep people alive at any cost [...] but I feel medical science is geared towards doing that. [...] I don't need my body to stay alive when it clearly isn't very pleasant anymore. [...] Everything is geared up to deal with somebody not being allowed to die. That's how things are set [...] that's almost their paramount concern [...] a big alarm goes off and everyone races to prevent someone from potentially choking.' (RTINT2, Judy)

As one commented simply:

'Sometimes I think medical science has established a way to keep the body going when the soul would rather be free.'

Conclusion

The most significant theme identified in this research was the overwhelming impact of the quality of relationship and nature of the interactions that residents and relatives have with staff. Staff provide significant emotional support to residents alongside their physical care duties and were deemed for many to be part of their social circle. Having fun with staff and knowing that staff cared about them was very important to residents in long-term care.

Relatives want to know staff and be known by them, to have their role within the care team recognised and respected, to feel part of the team and the community within the long-term care setting. Efforts staff made to make relatives feel welcome; to listen, be understanding and work with them as a team in the supporting of residents was especially important to relatives.

Both residents and relatives expressed consideration for the welfare of staff and their appreciation and respect for staff members' knowledge and skills. The contribution all aspects of care and therapy make to residents well-being is well acknowledged by both residents and relatives and their need for positive interaction and stimulation identified as being crucial.

A parallel key finding from this research was the emphasis that residents and relatives place on the long-term care setting being a community in its own right – a community given a framework through the physical environment (e.g. the layout and architecture of the facilities) but given life by the mutual support and friendship between residents, and particularly by the way in which the staff help support positive community and atmosphere in how they relate to residents, each other, and to families.

The wider issues discussed by families highlight that history is an important legacy, which those working with long-term care can address through recognising the impact that the pathway to rehabilitation and long-term care may have had on both resident and relatives. Learning from their experience could improve relations between staff, residents and families, improving their experience of rehabilitation and long-term care.

This research also highlights the importance of good physical care and therapy, and beyond that residents' need for interaction and independence, to feel connected to the wider world and to those around them and to have an environment that meets their needs, supporting the facilitation of day-to-day activities and community.

Residents and relatives are very much aware of the challenges of meeting the needs of everyone all the time within a long-term care setting; the tensions discussed in this research are testament to that, but through gaining a greater understanding of what is important, an ever improving environment and community can be fostered to meet these challenges.

It is usual to conclude research reports by making recommendations - but rather than go through this as a ritual in which the recommendations may not be 'owned' by those who would need to act on them we hope this research may lead to changes in other ways. We presented the report to service users and service providers involved in the research and a group have decided to meet to develop their *own* recommendations drawing on the findings from the research; we hope that this report will help to support the crucial trend towards putting service user perspectives central to services. We also hope to take the report to service funders and evaluators and discuss what recommendations they think are appropriate informed by this work.

Appendices

Appendix A

Question Design and conduct of the focus groups and interviews

The facilitator started by introducing the session, explaining the aim of the interview or the focus group and emphasising that people were free to participate, or not, as they wished in any part of the discussion. A simple voice check was performed and confidentiality and disclosure ground rules were set and agreed by the group. (The overall research ethical responsibility was outlined in the information provided to participants.)

The questions then used to prompt discussion in the focus groups and in the interviews were designed to be as open as possible at the outset of any data collection session – and then to prompt around a series of areas that the research team anticipated as being potentially important. These areas were developed, building on clinical, research and personal experience.

Despite the structure and question design, each focus group would be unique and facilitated in order to take its own path dependent on input from participants. The facilitator remained sensitive to the priorities of the research participants at all times, allowing them to take the lead on what they did, or did not want to discuss.

The question design was divided into four sections; the first section was orientated around a series of very open questions. For example, questions at the start of the session included, ‘What is important to you?’, ‘What do you like/dislike about your long-term care experience?’, ‘What aspect of care made/makes the most difference to you?’ Flexibility was required in order to provide participants with a variety of wording to ask the same question in different ways to help with understanding and to use participants own vocabulary.

The second part of the group discussion was designed to invite participants to consider what is important to them in relation to the four specific areas. These areas can be broadly categorised as:

- (1) social (e.g. opportunities for social connection),
- (2) movement (e.g. support for their own mobility),
- (3) sensory (e.g. hands-on therapy, the visual impact of the environment around them or specialist sensory areas i.e. sensory room),
- (4) functional/environmental (e.g. building access and facilities, activities and trips out).

Participants were prompted to consider each of these areas to try to open up a wider range of considerations than might have been prompted by Section 1 of the discussion³. The aim at this stage was to avoid leading the research participants as much as possible and only if such questions fail to generate responses, more specific and leading questions be used.

The third section of the focus group was designed to be the most 'focussed' and utilised one of the sub-methods as previously discussed. A set of cards detailing various components related to each of the four areas outlined were developed. For example, the cards included: individual room, therapy, large screen TVs, cleanliness, natural light, internet access, varied menu choices, friendly staff, in-house entertainment, and trips out. Participants were given cards and asked to put them in order of importance to them. They were also asked if they would like to add additional cards, 'what has been left out?' and, as appropriate, given blank cards and a pen to write their own.

The idea was that the card ranking exercise could be utilised in interviews and during focus groups, with participants working together to discuss the priority that should be given to each component, and explaining to one another the significance of each one. It was felt that this process of group discussion would be most revealing, rather than the actual final priority given to any individual card (which may, after all, be more a product of group dynamics than a reflection of any genuine group consensus) and would also serve as an 'ice-breaker' technique and be carried out prior to section 2 should section 1 not generate discussion.

The fourth and final section concluded the group with a reflective round-up and debriefing – to ensure everyone had said all they wished and were sure they had been understood. Participants were then thanked, and the session brought to a conclusion.

³ In adopting these categories to help structure the discussion we will be careful to avoid excluding the possibility of other areas, or other types of categories emerging as important. We will, for example, allow for the fact that the above categories may *not* be the meaningful category for participants – with alternative cross-cutting themes such as 'autonomy' being the key factor for them (this will be explored in the analysis phase).

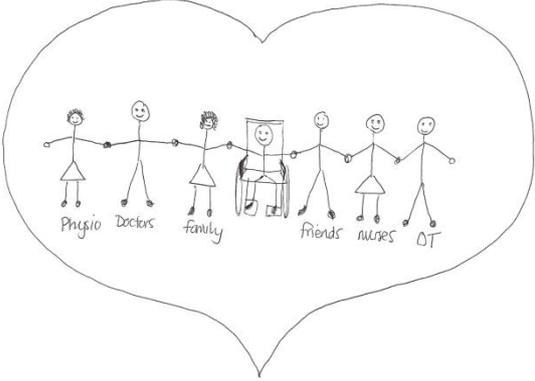
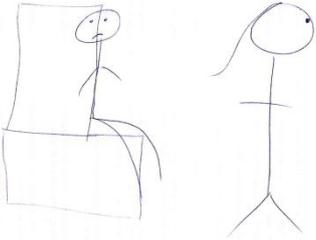
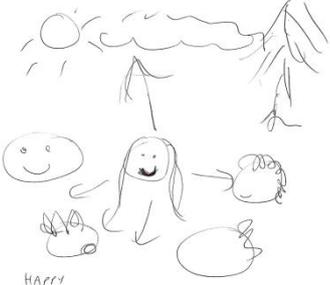
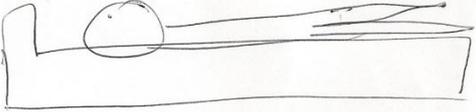
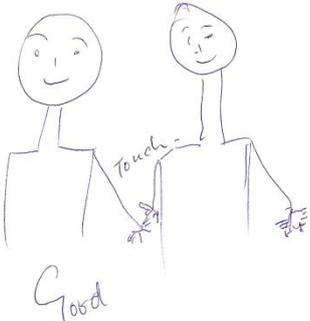
The focus groups with relatives followed the same process and addressed identical questions. The questions, however, were rephrased to allow them to give their impressions of what *they* thought was important to residents but with a primary focus on 'What is important to you?', 'What do you feel constitutes good care?', 'What helps you to feel comfortable/supported?', 'What helps you to be best able to support your relative?'

Interviews followed the same question design as outlined with the same open questions. Where possible interviewees were encouraged to set their own agenda and interviewers were sensitive to allow participants to discuss their thoughts openly while asking more specific questions from the question design as appropriate.

Due to practicalities and likely potential fatigue of this client group, it was felt that the likely time limit for most groups would be a maximum of 1.5 hours. The clinicians were surprised to find that resident focus groups lasted between 1.5 and 2 hours - with participants maintaining a high degree of engagement and energy to contribute to discussion. Similarly, although focus groups with relatives were scheduled to last only up to 2 hours, in practice enthusiasm for participation meant that groups lasted about 3 hours. Each group was audio recorded to allow in-depth analysis following the group and notes were also taken by the facilitator during the group sessions.

Appendix B

Examples of pictures drawn by research participants when asked to draw 'Good Care' and 'Bad Care'.

'Good Care'	'Bad Care'
	<p data-bbox="948 568 1203 607"><i>Not being bothered</i></p> 
	 <p data-bbox="855 1375 1043 1413"><i>that's it</i></p>
	

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