

UNDERSTANDING THE LIVES OF OLDER PEOPLE LIVING WITH FRAILITY *A QUALITATIVE INVESTIGATION*

IPSOS MORI FOR AGE UK
MARCH 2014



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FOREWORD

WRITTEN BY AGE UK

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Older people living with frailty are disproportionately affected by public and private services that are not geared to their needs. They are often the faces behind the headlines on poor-quality care; on avoidable admissions to hospital; and on the shameful statistics on isolation and loneliness. With this report, we set out to explore the reality of living with frailty with the people experiencing it.

“Frailty” is all at once a medical term, an adjective, a noun and for many, a judgement. Deciding exactly how we wanted to refer to it was an early challenge in pulling together this research with Ipsos MORI.

For the older people that participated in this work, it was not a word they associated with themselves. They all, however, had an idea of what it meant in others.

We use it here to capture a range of needs, typically underscored by reduced or reducing physical capacity. Perhaps more significantly, we also use it as indicating proximity to risk, i.e. a set of circumstances both social and biological, that means a shock or crisis could have severe consequences for someone’s health and wellbeing.

We describe this in more detail later in the report.

Importantly, we use frailty to describe something a person lives with, not what they are. We believe this is a vital distinction.

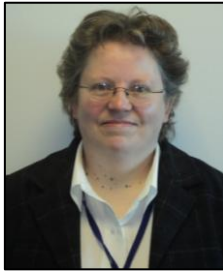
Society and services are organised around frailty as a *state*, often perceived as inevitable and irreversible, rather than a collection of modifiable health and social needs. As long as this mistake is made, then outcomes will continue to be limited.

This report does not represent all older people. Frailty is not age and age is not frailty, though many of the issues associated with frailty find common cause amongst a wide range of older age groups.

The people featured in this report also demonstrate that you will often find resilience and adaptability in facing some of the challenges that come with ageing.

However, older people living with frailty represent a group of people who are amongst the most vulnerable in society and who often are being let down by the services and communities they rely on.

The challenges that can come with living longer can be avoided, minimised or managed with the right care and support and a society organised to meet them. It is something we all have a stake in and we are pleased to make this contribution.



A handwritten signature in black ink, which appears to read 'Caroline Abrahams', written over a horizontal line.

Caroline Abrahams

Charity Director

Age UK



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INTRODUCTION

INTRODUCTION

“Our aspiration is for excellence, and for people to receive high quality, joined-up care, delivered with compassion. This means focusing on long-term sustainable solutions to improve care for the most vulnerable, particularly the frail elderly and those with long-term conditions.”

Source: Government Response to the House of Lords Select Committee on Public Service and Demographic Change Report of Session 2012-13: ‘Ready For Ageing?’ July 2013

There is a broad consensus amongst the Government, policy experts and practitioners that services for older people living with frailty need to adapt to meet their needs in the context of the demographic and economic challenges facing the country. In particular, there is a belief that services need to become more personalised, joined-up and preventative to best serve the interests of service users and work more cost-effectively in the future.

While experts often have similar ambitions for future policies and services, the implementation of this agenda can be challenging, particularly when public sector budgets are being squeezed and given there is limited evidence on what works for older people.

In light of this, Age UK recognise the need to be at the forefront of helping policy makers to understand the needs of older people living with frailty and have commissioned this research from independent researchers Ipsos MORI to demonstrate an up-to-date understanding of this population.

The research presented here explores the lives of older people who are living with different degrees of frailty and considers the factors that could have a positive impact on their quality of life. This report and accompanying films will have a valuable role in providing an in-depth picture of older people’s lives, whilst highlighting where their future needs may lie.

The report begins with a brief description of the research approach followed by detailed thematic chapters which cover the main findings regarding frailty, independence and control, support and assets, loneliness and isolation and adapting to life changes. The report concludes with a chapter written by Age UK, discussing the implications for policy makers.



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RESEARCH APPROACH

RESEARCH APPROACH

RESEARCH OBJECTIVES

The specific objectives of this piece of research were to provide Age UK with an understanding of, and insight into:

- commonalities and differences in the day-to-day life experiences of older people living with frailty;
- the overarching issues or problems from the point of view of older people living with frailty;
- what would help to improve the lives of older people living with frailty.

Many of the behaviours and feelings associated with frailty are best observed rather than described. Therefore, in order to provide a deeper understanding of what it is like to live with frailty, both ethnographic and qualitative methodologies were employed.

Five filmed ethnographic interviews were completed, followed by three 'discovery visits' to older people's day-centres where informal focus groups and depth interviews were conducted with people attending the centres. Finally, five follow-up depth interviews took place with participants who had consented to re-contact during the discovery visits.

DEFINING FRAILTY

An important challenge in conducting research into the lives of older people living with frailty was in defining who the population actually are.

Ipsos MORI worked with Age UK to develop 'pen portraits' which described the types of people we wished to engage with. Ipsos MORI and Age UK then worked closely together during the recruitment phase to ensure potential participants had suitable profiles to take part. More detail on how we defined frailty can be found in Appendix 1: Defining Frailty.

STAGE ONE: ETHNOGRAPHIC INTERVIEWS

Ethnography is a participant-led research technique that places as much

emphasis on observation as it does on questioning, allowing researchers to see first-hand what is important to participants. In this project, five older people were interviewed, along with family members and formal carers who were present on the day of fieldwork.

All interviews were filmed using a small hand-held camera as a means of capturing data about what people are doing as well as what people are telling us. In addition to field notes, this provided us with a wealth of data (25 hours of film) for analysis. Furthermore, having gained public-domain consent from all participants, we have included a film highlighting insights relating to each of the key themes explored within the report (see chapters 4-8), and further information about the participants who took part in the ethnographic and depth interviews in Appendix 4: Case Studies.

STAGES TWO AND THREE: ‘DISCOVERY VISITS’ & FOLLOW-UP DEPTH INTERVIEWS

Following the ethnographic interviews, research teams from Age UK and Ipsos MORI met to discuss and analyse the data. From this session, we derived key themes to follow up in the final qualitative stages.

Stage two involved researchers attending three older people’s day centres (two in the Midlands and one in the south of England). These ‘discovery visits’ allowed researchers to gain insight into the lives of older people within a supported environment.

Nine people gave consent to be re-contacted, which enabled us to interview a wider range of people (such as people from a lower socio-economic group, or living in an inner city area). Four follow-up telephone depth interviews and one face-to-face paired-depth interview were then conducted.

All interviews in stages two and three were audio-recorded and detailed field notes were taken. These recording methods provided us with a wealth of data for analysis purposes and enabled us to create five additional case studies, which, along with the ethnographic case studies, provide a backbone to this report.

Sample size and fieldwork dates can be seen in the following table.

| | | |
|---------|------------------------------------|----------|
| Stage 1 | 5 x filmed ethnographic interviews | May 2013 |
|---------|------------------------------------|----------|

| | | |
|---------|--|----------------------|
| Stage 2 | 3 x 'discovery visits' to older people's day centres (4 x focus groups, 1 x depth interview) | June and July 2013 |
| Stage 3 | 5 x depth interviews (4 x telephone, 1 x paired face-to-face) | July and August 2013 |

Please refer to Appendix 3: Detailed Research Methodology for further detail on the recruitment approach, fieldwork materials, fieldwork dates and safeguarding of participants.

OUR PARTICIPANTS

The ten case studies have been summarised below in order to set the scene for the report; further detail is provided in Appendix 4: Case Studies.

ETHNOGRAPHIC INTERVIEWS

Phyllis is a White, British woman aged 92 and lives in warden-managed sheltered accommodation in a suburban location in Greater London. Phyllis manages her home without the need of much support from others. She uses a walking stick to get to the local convenience shop to buy everyday goods throughout the week and takes a weekly scheduled dial-a-ride bus to her closest town centre for her larger weekly shop. Her daughter visits her every Friday and occasionally goes out with her.

Paddy, is a White, British woman aged 89 and lives in her own house in a suburban location in the South East. Paddy has carers who visit twice a day. She lives on the ground level of her home only, awaiting the installation of a stair-lift. Paddy receives additional occasional support from her three children.

Haydn, is a White, British man aged 84 and lives in his house in a rural location in the Midlands. Haydn receives informal support from his family, most of whom live next door to him or nearby. Haydn lives on the ground level of his Grade One listed home, as since a fall he is unable to walk up the stairs.

Lena (aged 79) and Malcolm (aged 80), are both White, British and have been married for over 50 years. They live together in their own house in a suburban location in the North East. Malcolm is Lena's sole carer.

Merle is a Black, Caribbean woman aged 79 and lives in her own home in a suburban location in the North East. Merle's son lives with her and helps her

with day-to-day activities such as cooking and cleaning. Merle has a stair-lift and receives informal care from other family members.

FOLLOW-UP DEPTH INTERVIEWS

Edward (aged 92) and Donna (aged 91) are married. They are both White, British and live in their one bedroom ground floor flat in central London. Edward is Donna's carer. They have a very close family network and visit a day centre every week. The day centre is run by a charity partially funded by the local authority.

Annie is a White, British, woman aged 68 who lives by herself in her own house in a suburban location in the Midlands. Annie visits a day centre once a week and receives support from friends and family. Annie uses a walking stick.

Mark is a White, British man aged 87 who lives in his own house with his disabled adult son in central London. Mark and his son support each other on a daily basis. Mark visits a day centre once a week.

Betty is a Black, Caribbean woman aged 80 and lives in her own flat in a suburban location in the Midlands. Betty visits a day centre twice a week and receives support from her daughter.

Natalie is a White, Irish woman aged 80 and lives in her own house in an urban location in Greater London. Natalie visits a day centre every week.

The data gathered from spending extended periods of time with these participants is used throughout the rest of the report to bring to life their lives and highlight where future support needs may lie.

It should be acknowledged that qualitative research is not designed to be statistically representative; it is intended to be illustrative, providing detailed and insightful levels of in-depth understanding around a research topic.



THEMATIC ANALYSIS

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ACKNOWLEDGING
FRAILTY

ACKNOWLEDGING FRAILITY



All participants were recruited on the basis that they were older people living with frailty (see definition in Appendix 1: Defining Frailty).

However, it quickly became apparent that direct conversations using the word ‘frailty’ were difficult to negotiate; it was family members or carers who used the word ‘frail’ to describe their relative and with whom frank conversations about frailty were easier. This does not necessarily suggest that they understood frailty in the same terms as a healthcare professional, for example. For instance Haydn, who sadly passed away within two months of being interviewed, did not see himself as frail:

- *“Do you think that you’re frail?”*

- *“I don’t think so – am I? Well. It depends where the frail comes in. Is it when you pick these up [touches walking stick] that you become frail? I don’t think so. I think it’s assistance really – don’t think it’s anything to do with frail.”*

Instead, participants spoke about finding everyday tasks more difficult to manage due to a collection of symptoms, such as pain and tiredness, and about how they needed help to maintain an active lifestyle. They said that life had “slowed down” and that they “could not cope” with the everyday tasks they once could. It was easier to have conversations about how life used to be and about activities that they used to enjoy. Articulating their present state was more difficult.

Merle, a devout Christian, described how she used to enjoy going to the church with her friend. Before going home, they would sit on the church wall together laughing and recounting stories. She also enjoyed going on trips with her daughter, but said that it was more difficult to go out now because of the

pain in her hip and the fact that she was unsteady on her feet. Merle said that she was scared that she might fall down if she went outside so she stayed indoors even on sunny days when she would have liked to go out.

Paddy, who needed support with movement and used a frame to aid her mobility around the ground floor of her house, also described how she was previously more mobile and used to drive to visit her friends. She no longer had a car, and could only leave the house with assistance. Paddy was also scared that she might fall going up the stairs so she was confined to living on the ground floor while she waited for a stair lift to be installed. She wanted to stay in her own home. She could not articulate what had caused her loss of mobility or did not like to mention it.

“I like it here. Not so easy since I got a bit, you know, not so easy since then. I mean a bungalow would be useful I suppose.”

Those who had experienced a significant event such as a fall, illness or stay in hospital could describe with clarity a state of ‘before’ the event and ‘after’ the event. The event in question then became a turning point and they referred to it as the cause of current difficulties rather than using encroaching frailty as an explanation. By contrast, a gradual decline in health and ability without a significant event as a marker was less easy to spot and harder to acknowledge.

For Lena, an operation on a brain tumour was a significant event following which she found everyday tasks much more difficult to handle. For Hayden, a fall which alerted doctors to a brain tumour was also a significant turning point. Paddy experienced a fall whilst on holiday with her family and had to stay in hospital for a long period. After her stay she needed carers to come in twice a day; a significant change in the status quo for her.

In contrast, Merle’s daughter, who spent a lot of time with her mother, suggested that she did not notice how much more difficult everyday tasks were for her mother. It was harder for her to see a change from one state to another as it was gradual.

“It’s dawned on me that my mum’s now 80, and she’s slowed down....this was the woman who said ‘come on Bridget, walk up now quicker’...and now it takes us four hours to do shopping trip that once took two.”

Although all these participants acknowledged that things had become more difficult, they did not use the word frail to describe themselves; ‘frailty’ was seen as something that other people lived with. They did describe others in

perceptibly worse health than themselves as frail, and often linked this state to death. This suggests that what frailty means to health and care professionals is not easily understood by the public, least of all the people who are defined as frail.

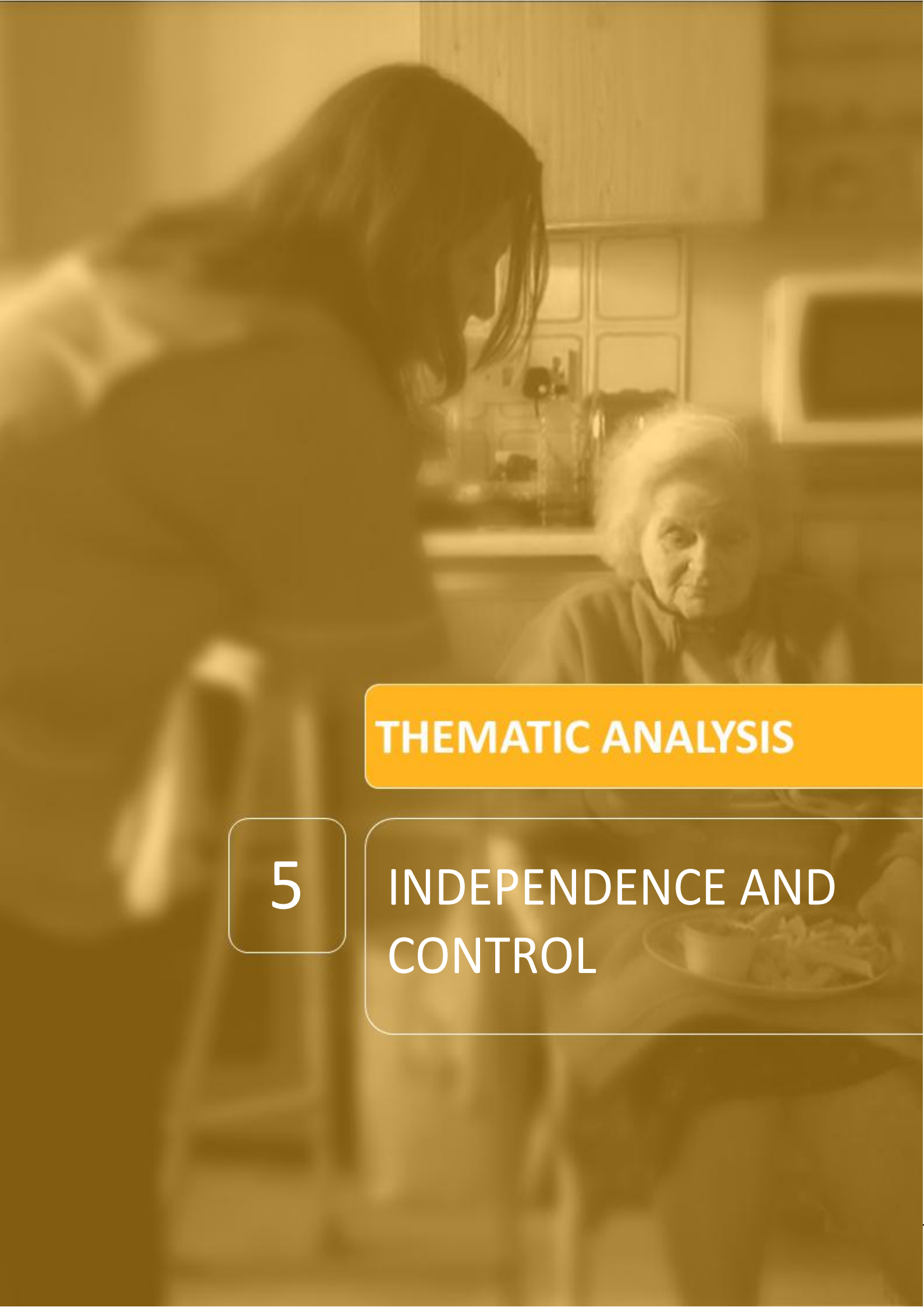
“To me, a frail person is someone like a skeleton that can’t move.”

“A few years ago my wife got discharged from hospital. The report said ‘a frail old lady of 88’. I said this is lies! She’s got more willpower and determination in her body than anybody I ever knew!”

We have found that participants’ own definitions of frailty are very different from formal and official definitions. This highlights a perception gap about what frailty means to those living with it compared to others, such as relatives and healthcare professionals. Whilst others can use the term frail in order to engage support services, the older person for whom this support is being arranged could be offended by the term.

CONCLUSION

Our findings suggest that there is a distinct difference between what healthcare professionals would define as frail (see Appendix 1: Defining Frailty) and the perception of frailty by the people they would define as such. However, this, and the fact that older people could acknowledge frailty in other people, does suggest that it is easier to *see in others* than to *accept in oneself*.



THEMATIC ANALYSIS

5

INDEPENDENCE AND
CONTROL

INDEPENDENCE AND CONTROL



There can be a fine line between accepting assistance, sharing a task and letting other people do things for you. This chapter explores how older people living with frailty manage everyday tasks and their desire to retain independence and control.

A social model of ageing would describe an individual's frailty as being caused by the way that society is organised rather than as a result of their health or disability. We observed that although participants want to maintain independence and control in later life, they find day-to-day tasks are increasingly harder to carry out. We observed many examples of how tasks can be made more manageable through slight alterations, either by the person themselves or those within the formal or informal support network.

MANAGING TASKS

By observing everyday experiences, we saw that there was a constant negotiation around maintaining control and independence between participants and their support networks. For example, after Lena's brain tumour operation, she found everyday tasks such as using the cooker to make the dinner increasingly difficult. Her husband, Malcolm now does the cooking and Lena still contributes by washing up the dishes. Lena mentioned this arrangement many times, suggesting that it was important to show that she was still contributing to the household chores. Equally, Malcolm encouraged it because he was aware that Lena should keep active.

Both Malcolm and Lena accepted the arrangement as a means of continuing to manage their home, and Malcolm stressed that things can be manageable if you help one another.

Accepting that routines have to change can also have a positive effect on independence. For instance, Phyllis takes a weekly stroll to the local shop rather than going to a large supermarket further away. This allows her to continue to buy everyday provisions without assistance from others, but at a pace and exertion that suits her.

Another example of negotiation was that of Haydn and his vegetable patch. As Haydn's family lived next door to him, they were aware that Hayden found a large garden difficult to tend. He described the larger area of garden that used to all be his and said that he "couldn't cope with it all really; it was too much for me". Haydn and his family agreed to share the plot, making Haydn's vegetable patch smaller and more manageable. This arrangement worked very well and enabled him to continue to enjoy gardening.

These stories demonstrate the value of negotiating a solution which enables individuals to retain control by continuing to engage with everyday tasks or scaling them down. This can have a positive impact on their wellbeing.

Finding a way to retain financial independence can be harder to negotiate. In our case studies and observations, carers were very careful to help the person they cared for to maintain control over their own money as much as possible. For example, we observed a day centre worker spending a great deal of time helping a service user to work out how much money she owed for the tea she had been drinking.

By contrast, Haydn was happy for his family to take over an element of his finances. He was finding it more and more difficult to deal with cash purchases. On two occasions, his family had to help recover money as he had given people the wrong change, often at great cost to himself.

"I gave her £40 instead of 40p, and she took it!"

Haydn's daughter Sally had taken control of his household bills by setting up direct debits and Haydn said that he had "complete trust in her to do this".

These stories illustrate that it can be difficult for families and carers to balance the need to safeguard and protect their loved ones, against respecting their choices, even when there was some risk involved.

INDEPENDENCE AND HOUSING

Sheltered accommodation can allow older people to remain independent

whilst having the security of single-level housing, built-in support equipment and easy to access emergency assistance. Even though there are clear advantages, moving into sheltered housing is not always an easy decision.

Those who had moved to sheltered accommodation felt that they had benefited from the move. They explained that their homes were warm and were easy to get about in. For example, a man using a day centre in Nottingham explained that his house had been adapted so that he could use his wheelchair at home. Some also valued having a warden service, as it offered peace of mind if they needed help or support.

“I must be lucky: I’ve got a lovely home [sheltered accommodation]. One kitchen, living room, a shower, one bedroom; it’s lovely. And if I need anything, I just call. And my neighbour, he comes round and does my garden.”

While such practical benefits may be immediately apparent, moving to a purpose-built property can require leaving a familial home which may house treasured memories and/or is near friends, familiar neighbours or family who can provide emotional support.

For Phyllis, her daughter asked her to move into assisted housing, in order to be closer to the family for support. Phyllis described feeling safer because the warden would check in on her to make sure she was okay. She also appreciated living close to other people of her age and being nearer her daughter. However, she felt that she had largely moved for her daughter’s benefit, rather than her own, and since moving had not been able to see many of her old friends. She also felt less confident in an area she was not as familiar with.

In general, those who had lived in their own home for a long period of time were keen to stay there even if it meant foregoing practical comforts such as a well heated home, easier mobility inside the property or fast access to help in an emergency such as a fall.

“I wouldn’t want to go into sheltered accommodation, because there’s no place like home.”

Paddy said she liked living in her own home, even though not being able to use the stairs meant she could not use the upstairs bathroom and had to sleep in the living room. Paddy had been waiting seven months to have a stair-lift fitted and hoped that the company involved would not take too much longer

so she could once again get upstairs as she particularly missed her daily shower.

These stories highlight the contrast between homes that are designed for those living with frailty, versus familial homes where whole floors can become inaccessible. Moreover, Paddy's story highlights the need to speed up the process of modifying homes to the requirements of an older person living with frailty.

CONCLUSION

Older participants who had accepted and received some form of support, be it housing or changing routines in order to cope with limited mobility, appeared to be more independent than those who did not. This could be because support which was offered in the form of partial assistance helped them to maintain an active life, rather than removing their independence completely.

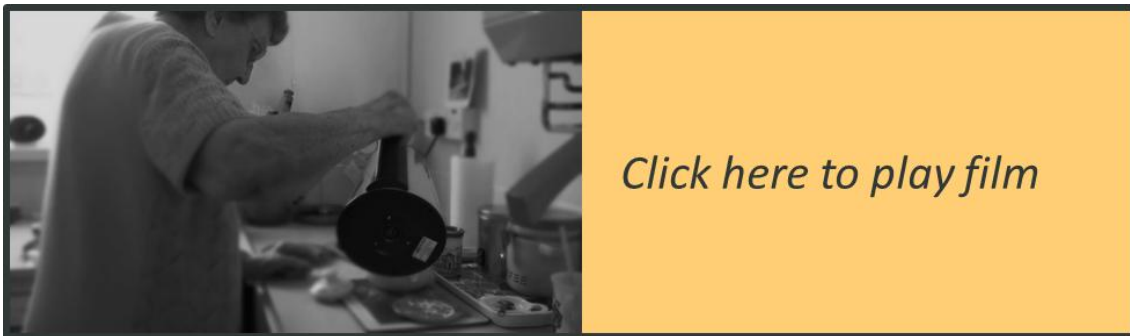
A person wearing a white lab coat and safety glasses is shown in profile, focused on a task. They are holding a pipette and appear to be transferring liquid into a small vial. The background is a soft, out-of-focus laboratory environment. The entire image has a warm, golden-brown color overlay.

THEMATIC ANALYSIS

6

SUPPORT AND ASSETS

SUPPORT AND ASSETS



The complexity and changing nature of older people’s lives supports the health professional¹ and Government² view that services should aim to be personalised, holistic, and as preventative as possible. The variety, extent and changing nature of older people’s needs, as illustrated in this report, can show how difficult this ambition can be to achieve in practice.

In general, support needs varied significantly, depending on a wide-range of factors, such as mental and physical health, cognitive abilities, social networks, financial capital, housing, previous knowledge and experience, cultural backgrounds and individual personalities and expectations.

SUPPORT SERVICES

Most of the older participants we spoke to explained that they were generally happy with the services they received from support agencies.

Betty had a number of health problems, including arthritis and high cholesterol. She had also been depressed in the past. Betty appeared to have less confidence and was less steady on her feet than many of the participants that we spoke to, but was still able to lead an active life.

Betty explained that she had felt very lonely and down when she first joined the day centre in Nottingham. At that time she had recently moved from London after she had found the area she had lived in “too hostile”. She had

¹ Royal College of Physicians ‘Acute Care Toolkit 3’, March 2012)

² Government Response to the House of Lords Select Committee on Public Service and Demographic Change Report of Session 2012-13: ‘Ready For Ageing?’, July 2013

used the day centre two days a week for the past seven years and the centre had had a very positive impact on her life.

“My daughter says I look totally different [since coming to the day centre]. You can tell. I didn’t want to come, but coming here is lovely. I didn’t like it when I first came because I have problems with my memory and I couldn’t remember the people, but I know them now, so I’m happier.”

The biggest benefit of the day centre for her was that she could meet and talk to a range of people. This service had a significant impact on her happiness and confidence, and she explained that as a result her overall health and wellbeing had improved. Betty said that she now had the “confidence to try things, while still being realistic”. By this she meant that she maintained a balance by staying active while acknowledging the fact that she no longer had the energy levels that she had had in the past. She also encouraged other people at the centre to take control of their own health and wellbeing by getting the right balance between being “brave” and pro-active and being sensible enough to take account of their own limitations (e.g. having a break when they needed one).

Not all of the participants we met attended day centres. In Haydn’s case, although he could see the value for others, he said he would go if he was “told to”. Perhaps this could have been because it signified a change from passively receiving support from those around him to having to seek it.

Merle did not attend day centres either; her daughter explained that this was because she felt the groups in her local area were not attuned to cultural differences.

“I think even with the organisations that do help the aged, they don’t take into consideration, I don’t think, the cultural differences. Not everybody goes to the same groups; not everybody wants to do the same thing.”

Never the less, these stories illustrate the positive impact that day centres can make on individuals’ lives - support which is likely to have had a significant preventative role. However this type of support is not suited to every individual, signifying a need for a personal approach when creating support plans.

UNMET SUPPORT NEEDS

Some participants had experienced health and care services which did not provide the support that they needed. The examples that follow show unmet needs within primary, secondary and community care.

The first example is Annie. She helped her neighbour after he had fallen over and damaged his knee. At the same time, it was clear that the neighbour had recently developed a problem with incontinence. Annie called a local GP surgery but initially found it difficult to persuade anybody to come out to help the neighbour. When a GP did arrive, he looked at the knee but offered little support beyond advising the man to take painkillers. The GP said and did nothing about the incontinence.

In Annie's opinion, some service providers would only help those who were very demanding. While she felt confident in this regard, her neighbour was less demanding and, as a result, only received minimal levels of support. Annie's neighbour died soon after the fall. Annie felt his life could have been prolonged if he had received better support and care. This story highlights the possibility of an unmet need for support from an advocate in some situations.

Another example of a patient feeling dissatisfied with support services was illustrated by Edward and Donna. Edward explained that his wife, Donna, had to spend some time in hospital following a fall, as she was not well enough to go home and their flat was unsuitable because she would have to climb stairs. Donna said she had very little stimulation in hospital and very little care from the staff. She liked talking to other people, but had few opportunities to speak to anybody outside her family. As a result, she started to become withdrawn and seemed down. Donna and Edward felt she would have been better off returning home, even though this meant a struggle with the stairs, as her husband and their wider family considered themselves better able to provide the stimulation and care she needed.

This same couple also believed that they had received poor support from home-care services. Donna's husband explained that the carers often came late, making it difficult for them to plan and maintain routine. Edward was also frustrated when he saw the carer taking breaks and felt that she did not spend long enough in the house, always giving the impression that she needed to rush off to the next appointment. As a result, he cancelled the services and they now manage without.

Other participants told similar stories. While some had very positive experiences, these instances highlight that unmet support needs can cause significant harm and dissatisfaction.

GIVING INFORMAL SUPPORT

Many of the participants we spoke to also cared for others, which had both positive and negative impacts on their wellbeing.

Mark explained that he had a role in looking after his adult son who lived with him. His son had a number of long term conditions. In recent years, as Mark had begun to struggle with everyday tasks, the two had begun to support each other. Mark believed that he benefited from living with his son as his caring role helped him to have a sense of purpose, enabling him to “feel younger” and stay active.

Malcolm cared for his wife, Lena, who was able to move around the house due to the addition of rails on the stairs and in the bathroom. Lena had very limited mobility and had become more or less housebound as a result. This meant that Malcolm kept himself very active by managing most of the jobs around the house. Malcolm also provided considerable emotional support for his wife, who was upset as a result of her reduced mobility. While Malcolm seemed optimistic, it was clear that he and his family were concerned about what might happen to Lena if he were to get to the stage where he could no longer provide her with the support she needed. In addition, Malcolm had very few opportunities for respite from the care he was providing.

These examples show that providing care and support as a parent or a partner can give a sense of purpose and help maintain a level of activity and stimulation. Services should however acknowledge that carers, sometimes in need of support themselves, may be making sacrifices in order to look after their partners or family members.

RECEIVING INFORMAL SUPPORT

Those receiving informal support from partners, relatives or children often benefited from this arrangement, as care was available throughout the day. In most of our case studies these informal carers seemed to have a good understanding of the needs, interests and abilities of their relative and were willing to meet them.

An example of this arrangement working well is illustrated by Haydn's family who worked together to ensure that he received all the support that he needed. Between them, his daughters would drive him to the shops, administer his medication, (sometimes injectable), do his washing and ironing, help manage his finances and engage neighbours and friends to visit him and provide friendship. The support that Haydn received looked to have a very positive impact on his wellbeing. Although he had terminal cancer, Haydn was able to maintain an active life, regularly seeing people, eating out, spending time in the garden, and looking after his pet dog.

Others relied solely on their family for help, but did not receive adequate support. Natalie had some support from her family but explained that it was unreliable, and she felt it was given without much enthusiasm. This sometimes made her feel she was a burden on her family.

"I don't get enough support. My daughter comes once a week and does the shopping, but she couldn't come this week so I didn't get any shopping. I can go to the shops but I have to think, will I be OK coming back?"

Natalie described herself as being very self-sufficient and independent. She seemed to be proud of the fact that she needed little help and was able to stay in her own home rather than sheltered accommodation. However, it was clear that she would have appreciated more help and support, and in particular, support that was more dependable and that was seen to be given more willingly.

These two contrasting examples illustrate the need for services to engage with the entire family unit when working out a support plan. This would ensure that the needs of older people living with frailty are met.

DEALING WITH FINANCES

It was clear that finances and financial security had a significant impact on the lives of the older people. We spoke to people in a variety of circumstances: some did not struggle financially, but many did find things difficult, with some explaining that they often got cold in the winter, as they could not afford to heat their house properly.

A woman from the day centre in Nottingham explained that she always kept the heating on even if she could not afford it as she felt her health should be her priority, and she "did not expect to be arrested for not paying bills at her age".

“My neighbour, she was elderly. You’d pop round and she’d be sitting with three blankets wrapped around her. She’d not have the heating on. She’d say, ‘Oh no’. I said, ‘I’m a pensioner too, but I put it on.’”

Merle had debts which made her very short of money. She was paying the mortgage on her house, having lost money as a result of a divorce settlement. Her daughter felt that the Government underestimated the impact of some people’s financial circumstances. Merle herself was not worried about money, but her family were concerned about whether they have the financial means to look after her if her care needs were to increase.

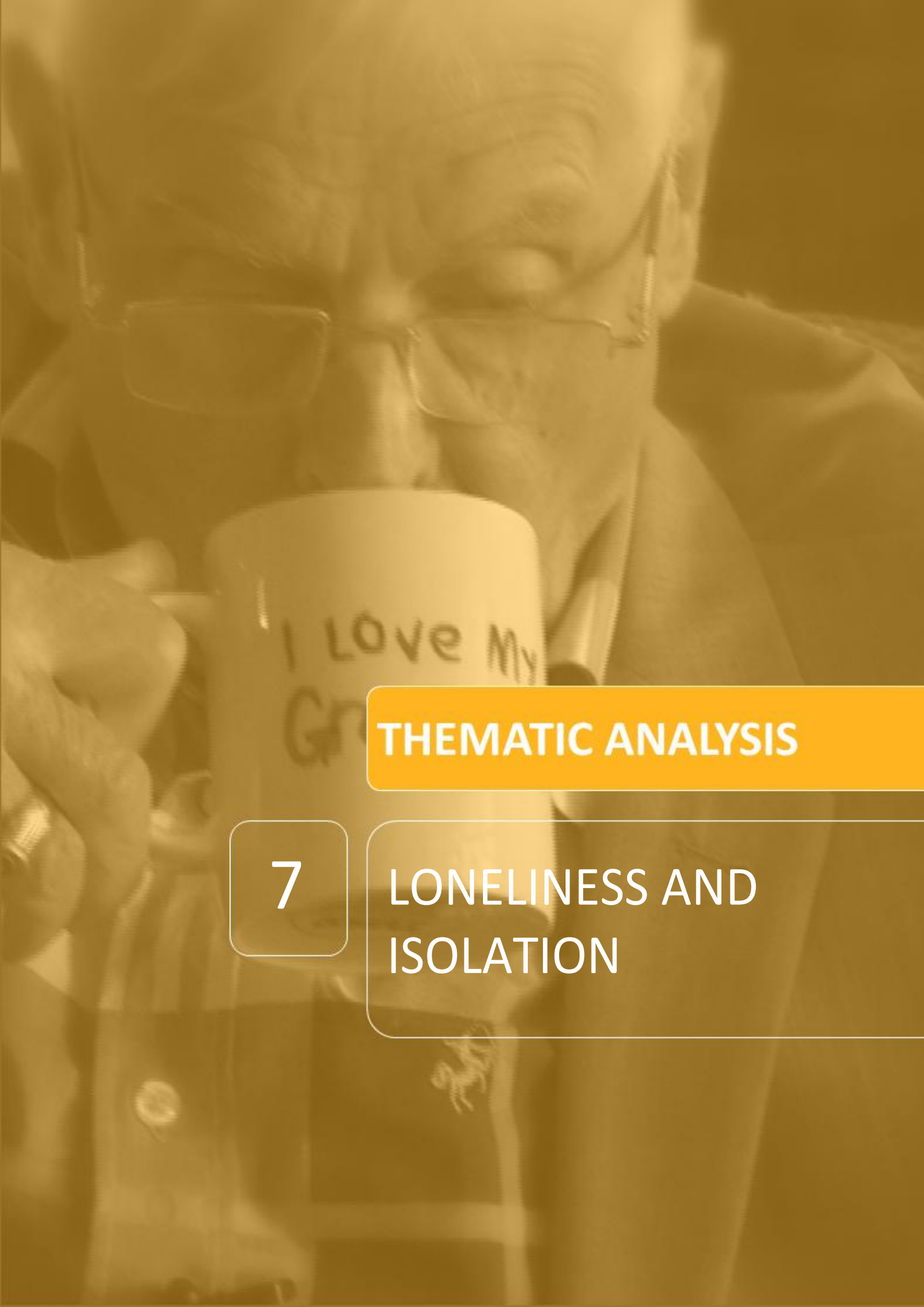
These stories illustrate that some older people do struggle financially. Although families can sometimes offer assistance, this can be a cause of stress as people worry about a future where demand for extra services and assistance may not be affordable.

TECHNOLOGY

Throughout the ethnographic interviews the absence of computers, internet access, and smartphones was noted. Indeed, contacting the participants for the research was all done over the telephone. This has ramifications for services wishing to use a model that includes some kind of online engagement or tele-health.

CONCLUSION

The wide variety of needs and circumstances among this relatively small number of older people reinforces the view that services should aim to become personalised, holistic and as preventative as possible. Recognising the diversity of their lives, the absence of technology and the impact that different types of support can have on an older person and other members of their immediate family is essential.

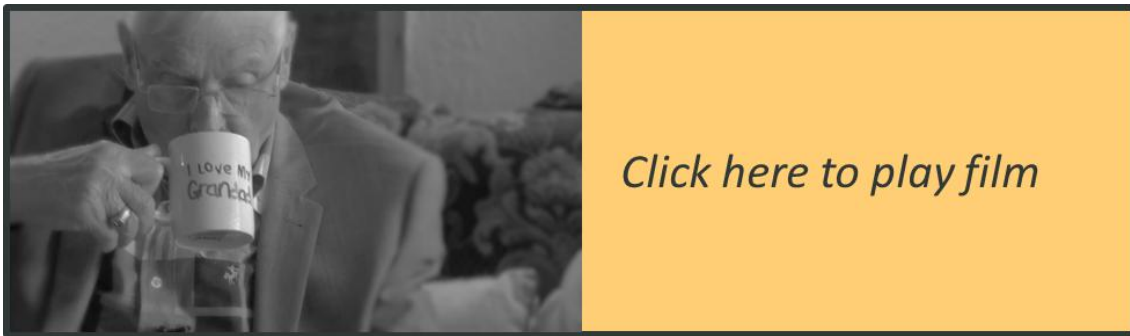


THEMATIC ANALYSIS

7

LONELINESS AND
ISOLATION

LONELINESS AND ISOLATION



This chapter explores the many ways loneliness and isolation can be experienced in everyday life.

GEOGRAPHICAL/PHYSICAL ISOLATION

When it is harder to move around or even leave the house, people tend to stay where they feel most comfortable and safe.

Paddy was confined to the ground floor of her house, used a walking frame to move around and had a care plan in place which included a carer who visited twice a day. It was clear that Paddy enjoyed the company of her carer, who explained that she enjoyed her job because it gave her a chance to talk to older people, who are often “crippled by loneliness”.

Paddy was also entitled to “companionship visits” where her carer could take her out somewhere for the day. However she was reluctant to take them, describing herself as “too lazy” to do so. We observed that she had limited mobility and tired easily, which perhaps contributed to her reluctance.

Paddy’s pastimes were reading in the afternoons and watching TV documentaries in the evenings. She said that would like a heated greenhouse, so that she could experience the outside without being too affected by the temperature. That would give her a lot of pleasure because she also missed gardening - an activity she greatly enjoyed until reduced mobility prevented her from continuing.

Reduced mobility also contributed to Lena’s isolation. Malcolm, her husband, had suggested that getting a wheelchair would enable them to go out together. However, Lena did not like the idea of being pushed in a wheelchair by her husband “in front of the neighbours”. Even though, from Malcolm’s

perspective, it would allow them to get out of the house and socialise as a couple, for Lena, it signified to the wider world that she was becoming more frail and she did not want to be seen in this way by other people.

“They want me to get a wheelchair but I don’t feel as if I’m ready for it yet. I certainly don’t.”

Lena’s wish to stay at home had a direct effect on Malcolm’s ability to socialise. Although he enjoyed playing table tennis twice a week at his local club, he felt torn when he left Lena. Before leaving the house, Malcolm made sure that Lena was wearing her personal alarm pendant and emphasised that he would not stay out for a long time. Malcolm still enjoyed socialising but missed having Lena with him and worried about her while he was away.

“Lena doesn’t go anywhere, even though I wish she would...”

“No; I can’t be persuaded. I’ve got the television.”

Paddy and Lena’s cases illustrate, that although older people living with frailty can feel more comfortable inside their houses, this decision can mean a lack of social interaction, stimulation and variety for both them and the relatives that care for them.

GENERAL SOCIAL ISOLATION

Amongst the people we interviewed, we observed that they generally lacked social contact, although some sought ways to remedy this.

In recent months, Phyllis had experienced a fall on public transport and described how it had affected her confidence in using buses, as she was concerned that the driver would not wait for her to sit down. She had stopped taking the bus to a local park where she had once enjoyed “sitting on a bench, eating my sandwiches and people watching.” Phyllis missed the feeling of being surrounded by people, even if she did not directly speak to them. To counteract this loneliness, Phyllis would, “go shopping - just to be in a shop with somebody else,” even though she did not then speak to people she saw.

Participants also placed a great emphasis on visits from their family and friends. Family is often of primary importance and can be the only window through which older people can regularly engage with others whilst feeling comfortable in their own space.

Lena, who described herself as “a stay at home” person, spoke fondly of visits from her family and the importance of this social contact in her life. Likewise, Merle enjoyed the company of her family who regularly came to see her, but said that although she would like to invite other people to her house she was embarrassed about a worn carpet that she could not afford to replace. For Merle, family members were seen as less judgemental and less stressful guests.

Haydn said the most important thing he could ask from life was “variety...because I’ve had everything else”. This was provided by company from his four children, who lived nearby, as well as visits from neighbours and old friends from work, who, upon hearing of his decline in health made time to “pop round and say hello”. Haydn’s family often went out to lunch with him and he enjoyed having a soft drink in the pub with his family and friends when the weather was not too cold.

EMOTIONAL ISOLATION

Even with the best will, support from family cannot truly replicate the experience of having a peer group and people with a shared understanding. The participants we spoke to in this study also placed importance on communication with those people who are friends, partners and peers. These are people with whom they can have a reciprocal relationship based on shared or similar life experiences and hence, share a mutual understanding.

Edward and Donna valued the relationships they had built up with their neighbours and friends. For example, Edward knew the people working in the local shops and Donna had become close to their neighbour.

“We exchanged newspapers with the lady next door. The next day she put a letter in for us. Now we’re very good friends. Inseparable.”

Some people had experienced sudden isolation and loneliness due to the death of a close friend.

Merle spoke fondly of the friendship a neighbour once provided who had recently passed away. Having someone who could walk at the same pace as her, stopping to talk and laugh made Merle feel more energised. Although her family were clearly very supportive and her grandsons would slow down to walk with her, Merle explained that since her neighbour had died, she felt that she no longer had any friends.

Phyllis had found herself in a similar situation, explaining that her only friend Rose had also recently died. She used to see Rose “almost every day... we used to go around together you know.” But since Rose’s death Phyllis’ life suddenly changed and she now spends most of her time alone.

Phyllis explained that a local group organised day-trips out of London and that she and Rose used to go on them together. Now that she did not have anyone to go on the trips with, she did not go on them as frequently as she was worried that when she got to the destination she may not be able to find her way back to the bus at the end of the day. Phyllis described herself as “a loner” and that she found it hard to make friends. Having “put her eggs all in one basket,” Phyllis explained how she missed the company and mutual understanding that Rose was able to provide.

Haydn felt a similar loss of mutual friendship, having had a “lady friend” that he used to visit when he was more mobile. His children had described this friendship as very positive for him as they used to keep each other company going out for lunch and on short trips to Wales. Since Haydn had become weaker and lost the use of his car, he was no longer able to visit her. Haydn’s daughter described this as “a real shame.”

“He doesn’t drive now, and he used to like going by himself almost every day to see her, and they’d go out for a meal and everything, which was lovely, but she’s not steady on her feet, dad’s not steady, so you can’t have two people like that, can you really?”

Some of the people we spoke to explained that their pets went some way to combat their emotional isolation.

Both Paddy and Lena described with great happiness how their cats had slept on their bed, emphasising the everyday joy that a pet could bring just by being there to provide company. Haydn described his dog ‘Harvey’ as “part of the family” and that he “keeps me on my toes” as he “nicks my sweets, nicks my hearing aid. I’ve got to keep my eye on him”.

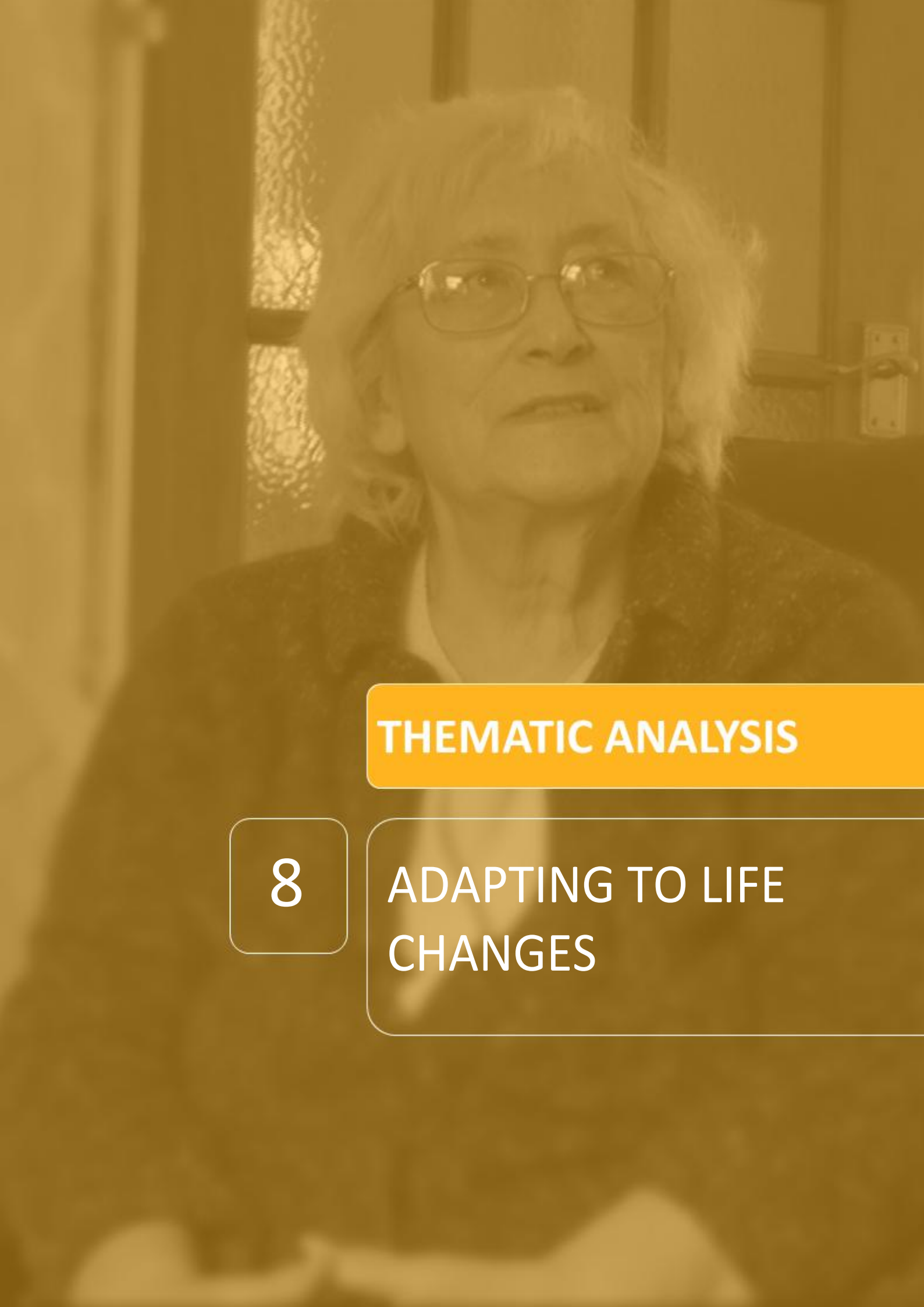
Sadly, Paddy’s cat, Maisie, died, but she had kept the cat’s toys and other related paraphernalia. Paddy wished that she could have another cat to replace Maisie but did not think it would be a “good idea” with reference to her loss of mobility.

These stories highlight how important it is for older people to have good friends with whom they can share a mutual understanding. The pleasure and

security that these interactions can bring cannot be underestimated. It is also important to understand that the death of a friend at this time of life, if social networks have become smaller, can lead to great unhappiness and a prolonged sense of loss.

CONCLUSION

The loneliness and isolation which we observed was made palpable during the research process as all participants commented on how much they enjoyed the company of the ethnographic researchers. This response to the research, in such emphatic tones, was unusual and underlined the importance of everyday company and conversation, especially for those with mobility issues who were unable to leave the house.



THEMATIC ANALYSIS

8

ADAPTING TO LIFE
CHANGES

ADAPTING TO LIFE CHANGES



This chapter explores the various techniques that older people use to deal with changing life circumstances.

RESILIENCE

We observed that humour and faith can make people feel better in light of life changes. Haydn kept a sense of humour at all times, which enabled him to make the best of difficult situations by staying positive. When his bed was moved downstairs and his clothes transferred to hooks on the back of the living room door, his response was to make fun of his new “walk-in wardrobe”.

Merle’s sense of humour, along with her faith, also helped her become more resilient in the face of life changes. Faith had a great effect on her mood. In discussing her financial constraints she looked on the bright side and said that although finding extra money to pay for services was not easy, she always had food in the cupboard and believed this was her Lord providing for her.

For healthcare professionals, being aware of culture, religion and personality, as well as an understanding of what is primarily most important to an older person, will be of great help when deciding on the best support to give.

COPING WITH BIGGER CHANGES

Life changes which cause a greater change in the status quo were not always easily accepted by participants.

Paddy had a fall whilst on holiday, which meant that she had a long stay in hospital. On returning home some months later, Paddy needed a lot of extra support and care and was no longer able to drive her car.

Paddy's new support arrangements differed considerably from how she had remembered her home life before the fall. Instead of accepting that a loss of mobility now prevented her from getting around as easily as before, she described herself as "lazy", whilst we observed that she actually looked tired and had very limited mobility. Paddy may have been in denial about her change of circumstances when she articulated her hope of getting another car, but further investigation helped us understand that a car to Paddy meant "freedom".

Paddy's story highlights that spending time with someone to explore the motives behind their desire for things, which look to be potentially out of their reach, could help in developing solutions to adapt to life changes.

WORK-AROUNDS

Likewise, encouraging people to find new ways to maintain an interest in their hobbies is important.

Natalie used to like keeping fit, but as she became older and less mobile she was unable to do a lot of the activities that she used to enjoy, so she has found alternative ways to stay active. For example, at the day centre, we observed that she helped the staff by clearing plates and tidying up, being around others seemed to energise her. She told us that she employed a cleaner at home, suggesting she had less energy there. She also kept in touch with her sporty-side through watching it on television rather than partaking, and through visiting sports venues where she once enjoyed taking part in sport.

"I go for walks. My son comes down and takes me out in Bethnal Green. My younger days were spent in the pool there."

Phyllis lives in sheltered accommodation and had adapted to life changes in many ways by making use of gadgets and using specifically designed services. She was aware of and used a weekly dial-a-ride bus which enabled her to go into the nearest town to do her weekly shop. There were other items around the house, such as a loud-speaker telephone with large numbers, which helped her with day-to-day tasks.

Phyllis also came up with creative solutions herself. She explained that she had recently started to get eczema all over her body and had started to use E45 cream daily to counteract the problem. She explained that she applied the cream to her back using a large ladle which she kept in her bedroom. She had

not told her doctor about her choice of cream or her invention, yet she seemed very proud that this workaround suited her.

Phyllis spoke of feeling safe when wearing her personal alarm around her neck. She explained that since Rose's death she had become more aware of her own personal safety. Rose, who lived in the same sheltered accommodation, did not like wearing the alarm or using the pull chords in each room. She hid the alarm in a drawer and tied the chords into balls. Rose died after a fall in the bathroom, unable to call anyone to her aid.

Understanding the day-to-day lives of older people living with frailty and the importance and significance of everyday activities, can help service providers understand how to best provide the support people need to adapt to change.

DEALING WITH DEATH

Conversations around end of life care and funeral planning can be difficult to approach, but we have found that if older people are open to discussing and planning, it is an area where they can retain some control.

Phyllis found the death of her friend, Rose, a great shock and described seeing the trouble and distress that the unexpected death had on Rose's family as incentive to get her own affairs in order. To this end, Phyllis bought her own funeral and was steadily getting rid of her possessions. She saw it as being helpful to her daughter, whom she still sometimes saw as "just a baby". Her natural instinct to take care of her daughter was instrumental in these plans.

Likewise, Merle felt that she was living on borrowed time, as she had outlived her "three score years and ten". She described talking to her family about planning for her death as very difficult.

Merle had negotiated help from her daughter in making a will, although her daughter explained her disappointment in how difficult this was and thought this would have been impossible for her mother to do had she not provided assistance.

A lady who attended a day centre in London explained that she felt it healthy to talk about end of life plans, but did not have family living nearby to have these conversations with.

"I think you should talk about it as much as you want to. If you talk about it, you know what will happen. You can tell them [family members] what you want and then they can go along with your wishes."

Those who were open to discussing funeral/will arrangements with us explained the pragmatic steps they had taken in their planning. However, many found it difficult to initiate these conversations with their relatives, so had made plans on their own, telling relatives where documents related to this were kept. This suggests that some older people living with frailty may need additional information or support to plan their funeral and / or prepare their will.

CONCLUSION

The definition of frailty for health care professionals focuses on the person's vulnerability or resilience to changes. For a person living with frailty, even small events can signify a step change in the status quo. We have seen that planning, and creating workarounds, can significantly enhance the day to day experiences and outlook of older people living with frailty.



9

CONCLUSIONS

CONCLUSIONS

This small-scale, ethnographic and qualitative study exploring the everyday lives of older people living with frailty visually illustrates how important it is for services to adapt and become more personalised, joined-up and preventative for users.

From the outset, researchers acknowledged the difficulty in defining frailty for the purposes of this study. With help from Age UK, a definition was drafted and agreed, and each participant was recruited on the basis that they met certain conditions that would normally indicate frailty. However, this is not a perfect science and finding effective ways to identify people living with frailty will be crucial in how services target support.

The research highlights a striking difference between what healthcare professionals define as frail, and how older people living with frailty define their current state of health. This difference is markedly starker in that participants in this study were able to point out frailty in others, and viewed this as a stage closely preceding death. With this in mind, the use of the term frailty, which may be useful as a medical definition, could be alienating to service users. That said, we have found that engaging in conversations pertaining to frailty, if necessary, can be easier to negotiate by or through close relatives.

We found that the older people we spoke to in this study did acknowledge that life had changed, and slowed down in terms of the activity levels they had been used to. As a consequence, participants had changed their daily routines to enable them to retain some degree of independence. Many examples of this were observed, from considerable levels of daily care, redistribution of tasks between family members, to changing shopping habits. Those who had moved to sheltered accommodation felt they had a higher degree of independence than people remaining in their familial homes; however this move was often seen to be at the loss of the emotional support that they might receive from their families and neighbours

When engaged with support services, such as day centres, participants told us that they had received good levels of support.

There were some unmet support needs when we focused discussion on healthcare and domiciliary services, with some examples of care falling below

an expected standard and resulting in poor outcomes.

There were several examples of older people living with frailty supporting others. Whilst this could have a positive effect on wellbeing, giving people a sense of purpose, and keeping them active, it was observed that these informal carers often sacrificed their own needs, and were perhaps overlooked by services in the shadow of their loved one who was in a significantly worse health condition.

The flip-side of this is that some receiving care often solely rely on their family members to provide this. Whilst we observed some examples of this working very well with family members providing high quality care to older people living with frailty, there were some examples of over-reliance on familial support which was unreliable, leaving gaps in much-needed support.

We observed many types of isolation and loneliness, namely, geographical, physical, general social and emotional isolation. We also observed many ways in which isolation and loneliness could be overcome; for example, visits from family members, carers providing companionship, day centres, and friendship from pets. However, the importance placed on peer support from close friends who can provide mutual understanding cannot be underestimated. Some of the older people living with frailty spoke about the great sadness and loss they had felt when such close friends had died.

All of the people we spoke to in this study had experienced life changing circumstances such as reduced mobility, a fall which greatly reduced their confidence, or a move to sheltered accommodation. However big or small the change, we observed many ways in which the older people living with frailty had maintained resilience. It was enlightening to observe some of the workarounds people had developed in order to maintain some sense of status quo and independence.

Surprisingly for the researchers, conversations around death and dying were, in the main, more acceptable to participants than were conversations directly about frailty. The pragmatic nature of some of the conversations around end of life planning might have been related to the fact that this afforded some control up until the end of life. This coupled with the fact that many people had been bereaved of at least one close friend or family member, may have weakened social taboos regarding death. In contrast, the difficulty in negotiating discussions pertaining to frailty could have been due to fear, anxiety or an unwillingness to acknowledge a loss of independence.



10

POLICY IMPLICATIONS
WRITTEN BY AGE UK

POLICY IMPLICATIONS

WRITTEN BY AGE UK

Because health can play a significant part in our understanding of frailty, it can often dominate any debate on the response to its challenges.

But as these accounts demonstrate, health and health services are only one part of the picture. If we are to deliver lasting improvements to the lives of older people living with frailty, there are much wider questions about how we organise services and society.

Ensuring Merle could leave her house, for example (see page 15), could mean providing physiotherapy for her hip and an assessment for a walking frame. She may need a medication review.

However, it may also mean advice on preventing a fall and support from the local voluntary sector to re-build her confidence. And it could also mean having someone to walk at the same pace with her and places in the local area that she wants to visit and are fully accessible.

This chapter outlines the policy implications of this research. Our recommendations fall into three areas, which we believe are the core objectives for supporting people living with frailty:

1. Maximising capacity and capability.
2. Personalising care goals.
3. Managing risk.

Many of these recommendations have significant implications for how we organise local services and how, for example, we train health and care professionals. However, given the likely increase in the numbers of people living with frailty as the population ages, the whole of society will need to adjust.

This will mean, for example, the healthcare system treating frailty as something that can be addressed and improved; banks and other service industries ensuring that their systems meet the needs of *all* their customers, including those living with frailty; local authorities, planning authorities and the building industry working together to develop places that mean that

people can stay independent for as long as possible.

MAXIMISING CAPACITY AND CAPABILITY

The participants in this research were on the whole resilient and adaptive. However, these traits can be undermined by how services operate, both day-to-day and during a crisis.

Where people were able to maintain a level of activity, while managing any complications that came with it, there was greater interaction with their communities and a healthier outlook. Where it was simply accepted that staying at home in a chair was the limit of their expectations, evidence of depression or physical decline was more apparent.

Services and communities must focus on ways to maximise what people are capable of rather than simply moving from one reactive intervention to the next.

RECOMMENDATIONS

1. Every opportunity must be taken to identify people that are living with or are at risk of frailty. This should lead to a detailed assessment of needs involving an older people's specialist team wherever possible. Acute and emergency services must also be equipped to carry out assessments.
2. Health and Wellbeing Boards should focus on pro-active support and improvement rather than simply maintaining the status quo. For example, rather than looking at the availability of services for single conditions, they must look across the spectrum of public services and local areas to examine how older people living with frailty can best be supported.
3. Community services should become multi-purpose. For example, GP practices could be linked to money guidance agencies or befriending and falls prevention services. Non-health services such as social care or housing services could be equipped to recognise signs of malnutrition.
4. Housing, including home adaptations, must be routinely incorporated into individual and local service planning. Leaving someone to wait for seven months, for a stair lift for example (see Paddy on page 22), is unfair on individuals and often a false economy.
5. Reducing loneliness must be included as an objective in all joint health and

wellbeing strategies.

PERSONALISED CARE GOALS

Health and care services will often be a touch-point for addressing issues linked to frailty and poor wellbeing in later life. Going into hospital, seeing your GP or having a social care assessment can be a moment at which needs are identified and a care plan put in place. They can also be moments when people are not listened to and their goals for care not sought.

We heard from Phillis how her GP continued to prescribe something she said she did not use. Paddy spoke of wanting to be able to use the second floor of her house but with little indication that this was being looked at with any sense of urgency, already waiting months for a promised stair lift.

The goals of people living with frailty can often be different from the goals of the people caring for them.

A GP may manage a set of conditions in clinical terms without full regard for the impact of being on multiple medications and the impact this might have on fatigue and mobility. If what is important to someone is to be able to leave the house and manage their own health as much as possible, then such an approach not only disempowers them but could also accelerate a decline in physical and mental health.

The whole ethos of care and support must re-focus on what is important to individuals.

RECOMMENDATIONS

1. Older people living with frailty and their carers should be encouraged and supported to discuss what is most important to them and this should inform any care or support package. This discussion does not necessarily have to be with a health professional though it must be built into the fabric of the local health and care services. The voluntary sector could play a key role in this.
2. All local services, particularly NHS and social care services, must invest in spreading approaches that embed shared decision-making. There is an extensive literature on how this can be achieved.
3. Older people living with frailty and their carers should have ownership of

care plans; usable information to help them manage their health and wellbeing, including access to supported self-management; and a clear point of contact when changes in their health or social circumstances occur.

4. As we age, we should all be encouraged to establish our wishes and preferences in advance of a crisis. This should include identifying what should happen if our health or personal circumstances change, such as losing capacity, and planning for end of life. This must be seen as a process of constant negotiation where everything from sudden deterioration to improvement is fully accounted for.
5. The quality of local services must be judged on their ability to support people to continue meeting life goals, regardless of their age. For example, social care or housing services should be assessed on the quality of the outcomes achieved and the degree to which these are coordinated across all areas of a person's life.

MANAGING RISK

A word that consistently comes up when talking about frailty is “risk”. This is often referred to as more of a defining feature of living with frailty than, for example, physical capacity. Living with frailty will typically mean having fewer physical reserves and being more likely to respond poorly to a crisis or trauma.

Someone living with severe frailty may be at less of a risk of injuring themselves if they move around scarcely at all, confining their activity to the smallest possible space. To reduce the risk of falling if they need to go to the toilet, for example, clinicians may consider that the best option is for them to be catheterised. However, while approaches like these may be reasonable and entirely appropriate in some situations, they may not be in all, particularly for prolonged periods. A local Age UK recently worked with an older man who had not left his house for ten years, a situation his local health and care services had been content with due to his physical health. By identifying that walking on the beach with his dog was a much loved activity and by providing volunteer support, this man finally, and safely, left the house.

Understanding risk also has an impact on decision-making around whether or not to treat someone. Evidence suggests that health professionals are less willing to treat older people living with frailty because they do not think they will recover or tolerate the side effects. This is often without any meaningful

assessment of their actual level of health or the offer of support to mitigate the risks. Services must approach risk management with older people living with frailty in true partnership with them and their carers and with proper regard to wellbeing, quality of life and a true picture of their needs.

RECOMMENDATIONS

1. Care planning for older people must incorporate risk as something which is managed rather than simply avoided. For example, older people living with frailty can be discharged from hospital with the single objective of avoiding harm at the expense of working towards achieving the best possible quality of life. This does not mean making unsafe decisions. It simply means raising the expectations of what is possible and working in partnership with older people and their carers to find the best way to deliver this.
2. If acute care services are not responsive in a crisis, the longer-term outcomes for older people living with frailty can be severely limited. The *Silver Book*³ includes good practice for when older people are admitted to hospital in an emergency and should be widely implemented. However, this must also include effective out of hours services and comprehensive support for carers.
3. Local authorities must work toward creating age-friendly neighbourhoods to ensure that everybody can participate in their local communities without, for example, fear of falling or being a victim of crime.
4. People expected to need a move to a care home should be assessed by an older people's specialist so that a strategy to avoid admission, wherever possible, can be developed.
5. Public health initiatives and messaging must do more to highlight frailty as something that you can change or reduce the risk of, irrespective of age.

³ http://www.bgs.org.uk/campaigns/silverb/silver_book_complete.pdf



11

APPENDICES

APPENDICES

APPENDIX 1: DEFINING FRAILITY

There are numerous tools used by healthcare professionals to define frailty, such as the Edmonton Frailty Scale and the Royal College of Physicians' Toolkit for acute care of older people⁴. Such tools could not be used for recruitment purposes for this research, as social researchers involved in this project do not have the medical expertise, nor are in the position to perform a comprehensive geriatric assessment. Moreover, a direct questioning approach would have been invasive to the participants and would not have satisfied our requirement to safeguard participants' wellbeing.

As there is no agreed definition of frailty, a working definition incorporating physiological and social factors was used to form a pen portrait description to recruit the participants:

People over 65, and probably much older than this, who struggle to do everyday tasks themselves and are becoming increasingly vulnerable to set-backs and difficulties.

They are likely to be finding it increasingly difficult to manage everyday tasks. A person living with frailty may be able to make a cup of tea, make the bed, or manage a utility bill but they are likely to be at a stage in their life when they find tasks like this harder to deal with. As a result, those without help and support may not be handling everyday chores very well or may be using adaptations or workaround solutions. Those who are managing tasks may find that they take up most of their energy, so they do little else.

They are also likely to be becoming more vulnerable to physical and emotional set-backs. Set-backs experienced will have knocked their ability to manage and their confidence, meaning they might find it very difficult to 'bounce back' from relatively minor difficulties, such as a cold or a stressful experience. In addition, they could be said to be one accident away from needing more intensive support or entering an end-of-life phase (if they don't already receive this form of support). For example, if a fall or health problem is likely

⁴ Royal College of Physicians. Acute care toolkit 3: Acute medical care for frail older people March 2012 <http://www.rcplondon.ac.uk/sites/default/files/acute-care-toolkit-3.pdf>

to result in a person needing intensive support, they are likely to be frail. Having experienced a fall within the past few years might have affected health or confidence.

In clinical terms, they are likely to have a number of different issues or problems, which, taken individually, might not be very serious but when added together have a large impact on health, confidence, wellbeing, etc.

Having established this definition of frailty, we used the following ‘pen portraits’ to describe four examples of people living in different sets of circumstances, whom we were looking to recruit. Each case was discussed and signed off by Age UK before interviews were confirmed.

Isolated older person – no support

Derek lives in a rural area and does not have any formal or informal support – either because he has been assessed as having low needs or has never had an assessment. He gets by but finds it difficult to cook and clean for himself, as opening packaged food and lifting heavy items like the vacuum cleaner have become difficult. Derek’s passion for history has meant he has accumulated and is still absorbed in his many books, which are scattered all over his house. He has never been married, or his wife passed away some time ago. He doesn’t have any children. Although he has been living in the same locality for most of his life, he has no remaining family, and his friends have either moved to a different area or passed away.

Local authority - minimal support

Sally lives alone in an inner city area and receives domiciliary care, which is funded by the local authority. Sally moved into her current home around five to ten years ago and has lived in this area for all of her life. Sally is frail and finds it very hard to get around without the aid of others. As a result, Sally tends only to leave the house when her daughter takes her shopping once a week. Afterwards, they share stories over a cup of tea and cake. Sally has occasional informal support from other family members. Sally has little income and is solely dependent on her pension and other benefits.

Helping each other

Fred and Margaret have been married for over fifty years. Fred enjoyed a

reasonably successful career and as a result the couple are able to enjoy an affluent retirement. They see their children rarely and therefore rely on one another for support. They both have a long-term condition. Fred uses a stick, so they have to take things slowly, but they are still able to get out and about. Although they don't visit any formal support services, they do manage to go to their local supermarket once a week, as Margaret can drive and they can park in the disabled bays close to the entrance. Fred is able to walk slowly around the supermarket when he holds on to the trolley and enjoys helping Margaret with the shopping in this way. The staff help them to bag the shopping and carry it to the car. They use the café there, stopping for a cup of tea before heading home again. They don't have any formal support from carers, but live in a caring community with neighbours they can call upon if need be. Some of the neighbours are of a similar age and they help each other out too.

Active older person

Miriam lives in extra-care or sheltered housing in a private or local-authority-run scheme and doesn't get many visits from family members. Since her husband died ten years ago, Miriam has been living for the days when she visits support services, namely, a twice-a-week lunch club and a once-a-month visit to a tea party organised by a charitable organisation. She enjoys meeting friends new and old at these events, and taking part in the activities such as knitting and using the in-house hairdresser.

APPENDIX 2: INTERVIEWING VULNERABLE GROUPS

Undertaking research with older people living with frailty (who are deemed a vulnerable population) needed a carefully-considered approach to recruitment and interviewing, to ensure the safeguarding of the participants. Therefore, informal routes to recruit participants were employed, meaning that potential participants were approached through contacts they knew and trusted, to make sure they felt reassured that they were taking part in a safe and genuine research project.

As an initial stage, all researchers within Ipsos MORI in the UK and Ipsos MORI's network of qualitative recruiters were contacted to explain the research project and how the ethnographic interviews would work. Once initial interest had been collated, individuals were telephoned to discuss the project and recruitment in detail. Full details were then sent in writing. These contacts then managed the actual recruitment.

Prior to the ethnographic visits, Ipsos MORI ethnographers called the participants (or their designated contact) to discuss the process and ensure any questions or concerns were answered. On the days of the interviews, informed consent was sought before beginning the ethnographies and signed consent was gained at the end. Furthermore, the participants from the ethnographic interviews have had the chance to watch and 'sign off' the footage prior to publication of this report.

By definition, an ethnographic research approach means researchers spend long periods of time with participants (in this case, five to six hours), and although participants are asked to carry on with their everyday lives, interaction with the researcher is necessary to facilitate data-gathering. With this in mind, participants who could be deemed as living with very severe frailty (such as those with later-stage dementia, who may not have been able to engage for longer periods of time) were excluded from this study.

As usual with ethnographic interviewing, researchers spent time during the start of the interview getting to know the participant and building up rapport and trust. Once more, given the sensitive nature of researching vulnerable populations it was deemed appropriate as a safe-guarding measure to telephone each of the participants to check on their wellbeing shortly after the fieldwork had been completed.

APPENDIX 3: DETAILED RESEARCH METHODOLOGY

ETHNOGRAPHIC METHODOLOGY

In order to determine whom to recruit for this stage, pen portraits were designed describing the types of people we wished to speak to, as outlined in Appendix 1: Defining Frailty. Pen portraits are not set-in-stone definitions but provide vivid descriptions, which include information about the participants' potential habits, behaviours, lifestyle, demographic characteristics, and attitudes. We find that these pen portraits are more helpful than simple screener questionnaires, in enabling both researchers and clients to visualise the kind of people we propose to recruit.

Alongside the pen portraits, we sought to incorporate other quotas, so as to ensure that the participants we recruited represented a diverse cross-section of society. With this in mind, we included minimum quotas on: age, gender, rurality, household structure, ethnicity, financial circumstances and access to support. Furthermore, it was important that these visits were conducted across England, the breakdown being as follows:

- One interview in South East England
- One interview in Greater London
- One interview in the East of England
- Two interviews in North England

We conducted five-to-six-hours-long ethnographic visits with each participant. These interviews took place between 2nd May and 24th May 2013.

The interviews were led using a discussion matrix, which gives guidance to the researcher on the types of questions we would like to answer and observations we would like to make. A summary of the topics discussed are outlined below:

- Daily routine
- The impact of frailty
- Finances
- Carers and other support-workers

- Living with long-term conditions and other ailments
- Healthcare professionals
- Medication
- The future

DISCOVERY VISIT METHODOLOGY

In order to determine which centres to recruit for these visits, Ipsos MORI worked with Age UK to target centres of interest. Once this initial sampling frame was agreed, Ipsos MORI approached the centres via email or telephone, giving background information on the project and detailing how they could take part. Once this interest was collated, researchers called the centres to conduct a short interview about their target populations. The final sample of three centres was agreed with Age UK, in order to fill any gaps in the quotas left by the ethnographic stage. We targeted two urban centres, plus one additional urban centre with a higher population of BME older people. As with the ethnographic stage, it was important that these discovery visits were conducted across the UK, the breakdown being as follows:

- One discovery visit in a day centre in Nottingham
- One discovery visit in a day centre for a BME community in Nottingham
- One discovery visit in a day centre in East London

Once recruited, we conducted two group discussions (lasting around an hour), and shorter depth interviews, with a wide variety of centre-members.

Centre Managers introduced us to participants and explained why we were attending that day. They were also on hand for any questions the centre members had. In some cases, staff acted as translators for groups where the population didn't speak English as a first language.

A summary of the themes explored is outlined below:

- Commonalities and differences - To what extent are experiences the same or different?
- Drivers - Why do people become frail and what can they do to

improve their self-efficacy?

- Motivations - What things motivate or encourage people and what happens when traditional motivators no longer work?

Researchers were equipped with a discussion guide and case studies developed from the experiences of the ethnographic participants, detailing suggested topics and examples for discussion. The case studies enabled us to use projective techniques to understand potentially sensitive topics. Participants were asked to comment on the case studies, stating, for example, if anything about the case study was familiar to them, or if they would give the person in the case study any advice. In general, we found that participants were happy to share their personal experiences, as they knew each other well and were comfortable in each other's company. In addition, participants with more limited energy, or reduced memory often found it easier to discuss their own experiences than tackle a more abstract case study. As a result, the case studies were not heavily used.

At the end of the discussions, participants were asked if they were willing to undertake a follow-up telephone interview at a time convenient to them. Nine people provided re-contact consent.

APPENDIX 4: CASE STUDIES

PHYLLIS**Age:** 92**Location:** Sutton**Support:** Warden-managed retirement home; uses a walking stick

Phyllis is a traditional, fiercely-independent, resourceful, yet cautious older person. She is recently bereaved: her friend Rose, who lived in the same retirement complex, died after a fall in the bathroom. This has affected Phyllis greatly. In one way, it has made her more aware of her own safety, but it has also made her much lonelier.

Phyllis is worried about travelling on public transport, due to recently falling over and injuring herself on a bus. She also feels intimidated by large groups of young people who travel to and from school on a bus route that she used to use. She avoids this route now, preferring to walk further to another bus stop. Phyllis does go on organised trips and attends coffee mornings and other events at the retirement complex but, since Rose's death, she enjoys her own company, rather than that of strangers. She describes herself as a "bit of a loner".

As Phyllis lives in housing which is adapted for the needs of older people, she has a few gadgets to help her with everyday tasks. She also uses a kitchen ladle to apply cream to her back, which helps to stave off eczema. She is very pleased with her invention. She hasn't told her doctors about the cream she uses or her invention, as she doesn't feel that they would be particularly interested.

Phyllis feels very strongly that older people are not listened to by the rest of society - she feels that she doesn't have a voice.

What matters most to Phyllis are her relationships. She is very proud of her grandchildren and has a lot of contact with her daughter.

PADDY

Age: 89

Location: Guildford; own home; bed downstairs

Support: Carers twice a day; waiting for installation of stair lift; additional support from three children



Although Paddy appears pale and is unsteady on her feet, her keen intellect comes across in conversation. When speaking, she uses short sentences and her voice is quiet and contemplative. Her life, once full of activities such as seeing her friends, attending to her house, garden, various pets and work, is now shrinking and simplifying. She can no longer manage stairs so she lives on the ground floor of her two-storey house while she waits for a stair lift to be installed. This means she can't use the upstairs shower so she has to have a wash, with help, downstairs. The fact Paddy lives in the house that has been hers for twenty years accentuates her changing mobility, as part of her own house is inaccessible to her. What is very apparent is the strain to complete normal tasks. Carers come twice a day to help with washing and cooking.

Paddy is no longer able to drive but sincerely wishes that she could. The freedom she craves from having a car would lead to an expansion of her world, as she says she would visit friends and market towns to see the sights and do her shopping. The last time she went on holiday to the seaside, she fell very badly. She doesn't think she can now enjoy the holidays by the sea that she used to love. She dreams of living by the sea but doesn't think this is possible.

Perhaps it is because she cannot leave the house alone that she has got out of the habit of doing so, even with assistance. Her carer has to convince her to take the 'companionship trips' that can be so beneficial and do seem to make her happy.

Animal welfare matters most to Paddy. She misses her cat Maisie, who died some months ago. Unopened cat food and an empty litter tray are constant reminders of the loss of her companion. She dreams that she will have a new cat.

HAYDN

Age: 84

Location: Cambridge; own home; bed downstairs

Support: Medical, social and financial support from family; large social network



Haydn is an engaging, chatty man who has retained a good sense of humour in the face of illness. His family busy themselves around him, showing how, with sustained and varied human contact, Haydn can be supported to enjoy an active later life. He has lived in the same house for many years and his five children can engage their own friends and family who can also offer assistance. They all live close by, visit every day and are able to get further support from friends and neighbours if needed.

Haydn's children help him with collecting his pension, cooking his meals and washing his clothes. His daughter Sally handles his finances and her sister Alison gives him his medicine/daily injections. She relieved the district nurses of the duty when it was realised that the injections would be needed every day.

Haydn cannot walk without a stick and cannot go by himself to the shops, but his family rally around, enabling him to live as full a life as possible.

He enjoys walking in his garden but is frustrated that he can't "work" more.

Even though his family support him a great deal, Haydn says he finds it difficult to ask his children to help, as he says they must be so busy. He always says, "I'm alright," when asked about his wellbeing.

Haydn would not consider himself frail, even though he can no longer get up the stairs of his house, has to walk with a stick, needs to use a wheelchair to go to the garden centre, has his daughter look after his medication and is transported places by car. Frailty is what other older people suffer from - not him. His daughter would describe him as frail.

His greatest needs are variety and stimulation, which his family and visiting friends provide. He also gains pleasure from the company of his dog, who "keeps me on my toes".

LENA & MALCOLM

Age: 79 & 80

Location: Leeds; own home; bed upstairs

Support needs: Malcolm is Lena's carer



Lena, in her own words, is a "stay at home person". Her life has changed significantly in the past couple of years, due to her reduced mobility, but she does not want to be seen as an "old person" who can't do things for herself. Lena's physical frailty means that she is socially more isolated, but she does not mind this. Malcolm is the one who wants her to go to the club to listen to live music, but she is not interested. Having said this, she is aware that "clinging to the house" might not be very good for her.

Lena is cared for by her husband, Malcolm. They have been married for 57 years. Malcolm does a lot for Lena. He makes all meals, apart from breakfast. He also gives her her pills and helps her into the car if they go on trips. She can walk up the stairs with the use of handrails but it is a significant effort. She uses a special chair that has electric leverage, in order to help her get up and sit down. Malcolm is happy to help, but Lena finds that it is difficult for her to ask him. Malcolm makes her life, even though it is very static, full of company, love and care. If something happened to him, reducing his ability to care for her, then she would have to go into a home, which would be very significant.

Malcolm realises that doing absolutely everything for Lena could cause her to stop completely, so he does make sure that she continues to do what she can, otherwise she will "seize up". He asks her to do the washing up.

Lena does not want to accept that she is frail. She does not like the idea of a wheelchair or a stair-lift because it would signify that she is moving into a stage of her life that she does not feel comfortable with.

Company matters most to Lena. She says support from her family and company from her cat are very important.

MERLE

Age: 79

Location: Leeds; own home; bed upstairs

Support needs: Stair lift; informal care from family members; her son lives with her



Merle is a devout Pentecostalist, and her faith plays a big role in her life. She says that without her belief she would have “gone mad”. She explains her thoughts and feelings about her social and financial situation with references to the Bible. Having outlasted her “three score years and ten”, she feels that she is living on borrowed time. She thinks about dying and is concerned about the financials of her funeral arrangements; however, she feels that her family do not like discussing this with her. Her thoughts do not seem morbid, but rather she is excited to be moving closer to God.

She survives on her state pension, as well as contributions to the household from her son, who lives with her. She still has a mortgage to pay because of a divorce settlement with her ex-husband who moved back to Jamaica. Her family help her meet these payments. She sees her daughter almost every day. A member of the family will come round and do the cooking for her and her son does the cleaning. She is able to wash and dress herself but spends most of the day watching television or lying down, as she has low energy.

Talking during the interview, which at first seemed to tire her out, ended up making her feel invigorated, and she described at the end of the day how she felt much more refreshed than she would usually. She does not find it hard to ask her family for help but does appreciate that they have jobs and are busy with their own lives.

Merle highlights the fact that it is hard to find someone who can walk slowly with her if she wants to go somewhere. She says that her grandchildren have the patience to walk slowly but also suggested that it was easier when she had a friend to walk with who also needed to move slowly. Her friend recently died, so she misses this companionship and the camaraderie of another person who was in a similar physical predicament.

EDWARD & DONNA



Age: 92 & 91

Location: London

Support: Edward is Donna's carer; they have a very close family network and visit the day centre

Edward and Donna have been married since 1946. Edward cares for Donna, who has diabetes and is experiencing the early stages of vascular dementia. Donna often forgets things but likes to recount tales from the war, as she remembers them clearly. Edward thinks nothing of caring for Donna, but ensures she pulls her weight. For example, he does the cooking and Donna does the washing up.

They live together in their one-bedroom ground floor flat, which they moved to a couple of years ago, when Donna came out of hospital and could no longer manage the twenty concrete stairs up to their previous flat. Their home does not include any modifications, such as grab-rails; however, they do have a phone with oversized buttons.

They usually do everything together, however, in recent hot weather, Donna has become very tired, so has had to stay at home while Edward walks to the shops to run the week's errands. This has not gone un-noticed by the local shop-keepers, to whom the couple are familiar faces.

They are an extremely close couple who have a very strong support network of friends and family around them, and, as a result, have a very active social life. They both enjoy their visit to the day centre twice a week. After each visit, their sons call up to discuss the activities that they have been doing. Edward and Donna take great pleasure from this.

Edward had to give up driving two years ago. This meant they have had to sell their holiday caravan, which they used to visit regularly. They are still able to get around town but rely on their family for lifts. Due to his poor eyesight, Edward is also no longer able to read or complete puzzles, which he used to enjoy. The television is now their main source of entertainment.

They have had mixed experiences of the NHS and home care. They were frustrated by the lack of time allocated to carers on visits. They are also frustrated by medical staff using technical language and not explaining things clearly. Edward feels that older people are often forgotten about, and that this has to change.

ANNIE

Age: 68

Location: Nottingham

Support: Day centre visit once a week; support from friends and family; walking stick



Annie used to live in a larger house; however, after her daughter moved out, she was the victim of an attempted break-in. This scared her, so she decided to move to a smaller house, and is now happy in her one-bedroom bungalow.

Annie values friendship and has a best friend who visits her regularly. She says she does her best to look out for other people in the hope that they will do the same for her: “I see people in trouble and I think, ‘That could be me one day!’” Recently, she found one of her older neighbours was unable to keep her house clean and tidy, so Annie called the council, who send someone round to clean it for her.

Although she has a daughter, Annie is reluctant to be too reliant on her, as she feels she has her own problems to be dealing with. Annie goes to visit her daughter every week, but it is rare that her daughter comes to see her. She would like to think that her daughter would be there if she needed her, but she’s not certain. She feels that family do play an important support role, and that it is important for people who do not have family to have someone else who comes to check if they are alright.

She has had a difficult life – her mother died young, leaving Annie to look after her three younger siblings. Aged 30, she split up with her husband and subsequently had deterioration in her mental health. In her own words, she still has “good days and bad days” but has found ways to manage her stress, avoiding certain situations and taking prescribed medication, which helps her moods but causes tinnitus.

Annie had a kidney infection last year but has told her doctor that she no longer wishes to take medication for it, as she doesn’t like the side effects. The after-effects of the infection, combined with on-going difficulties with her ears, mean she often experiences vertigo. She therefore walks with a stick to keep her balance when she gets wobbly on her feet.

Despite this, Annie likes to keep as independent as possible. She gets around by bus, and thinks her bus pass is fantastic, as it allows her to have freedom, meaning she does not have to rely on people.

MARK

Age: 87

Location: London

Support: His son lives with him; they support each other; visits day centre once a week.



Although Mark knows he is getting older, he believes you have to “act young to stay young”, so tries to keep active and dress smartly.

As a result of smoking, Mark developed emphysema and has lived with it for two years.

Mark lives at home with his son Graham. Graham is 54 and has epilepsy, as well as having a condition which affects his manual dexterity. Mark and Graham therefore care for each other, helping each other out with the things that they find difficult. As it is dangerous for Graham to be around hot objects, Mark does the cooking, while Graham is in charge of housework. Mark makes a lot of salad, cooking a hot meal about three times a week.

Mark also has a second son, who lives nearby and has his own family with children and grandchildren. They visit Mark every weekend.

Every Wednesday and Friday Mark walks the short distance to the shops with Graham and they buy the week’s supplies together.

Mark enjoys getting out and about. He takes pleasure from going for walks, and finds they help improve his mood when he is feeling a bit down. He often takes the bus to the park, then walks home, but doesn’t walk both ways, as he feels that would be too much for him. On Saturday nights he walks to his local pub for a couple of pints, but he does not drink heavily.

BETTY

Age: 80

Location: Nottingham

Support: Visits day centre twice a week; daughter



Betty is an Afro-Caribbean lady. She used to live in London but moved, as she found the area too hostile. She has one daughter who lives nearby, but the rest of her family are still in London.

Betty values her independence: she likes to get out, taking walks when she can and using the buses to get around Nottingham. She sometimes travels down to London by herself on the National Express to see her family. It is very convenient for her, as she can get the bus from outside her house to Nottingham bus station and on to London from there.

Although Betty does do some of her own cooking, she relies on her daughter to do the weekly shop. Her daughter also makes meals for Betty and freezes them in individual portions for Betty to re-heat as necessary.

She has high cholesterol, so keeps a healthy diet, eating a lot of fruit, vegetables and low fat foods.

She has severe arthritis, for which she has been prescribed medications, however she does not take them that often, as they cause unpleasant side effects. Instead, she takes dietary supplements and painkillers when necessary. Her arthritis means she gets up very early in the morning to do exercises and get ready for the day, which takes her a long time. When she worked, she used to do exercise classes at lunch times, and being used to regular exercise, she likes to still keep some kind of routine.

Betty visits the day centre twice a week and has done for seven years. She says: "The day centre gave me a new life." She states that these centres help people to socialise, preventing isolation and stopping people from losing track of what is going on in the world.

Betty is generally very happy with her life. She advises people to look after themselves, to work hard and not to be afraid. She says it is important to be realistic in what you are doing, and to be sensible with money, food and drink.

NATALIE

Age: 80

Location: London

Support: Day centre



Originally from Ireland, Natalie moved to London in the 1950s. She now lives alone in a flat that she has owned for 40 years. She is very proud to have the independence of living in her own home, and despite struggling with severe arthritis and lupus, she would not like to move into sheltered accommodation.

A recent dispute with a noisy neighbour caused Natalie a lot of stress. If this had happened ten years ago, Natalie might have considered moving, however, she has now ruled out this option, as she does not want to unsettle herself.

Natalie divorced her husband some time ago, and although she has a large family, she feels they are not really there to support her. One of her daughters does visit weekly, but Natalie feels this is only out of “duty”. Natalie has therefore learnt to manage by herself, and is not comfortable relying on others. Generally, she says she is happy being by herself, as she has always been that way, but she would appreciate some company, perhaps a friend, when she goes out and about.

Natalie has a long history of depression and anxiety. She had a breakdown in 2000, and although she has mostly overcome it now, she still experiences manic and depressive moods.


Although Natalie appears relatively fit and mobile, she is unable to do a lot of the activities that she used to enjoy. She has had to make compromises. For example, she used to play a lot of sport; now she watches it on TV and supports Manchester United. She is also no longer able to do the housework, so has had to employ a cleaner.


Natalie places a lot of value in the day centre that she visits twice a week. She enjoys talking to people there, although she sometimes gets frustrated, as she feels some of the people who attend should not be there because their physical limitations and/or difficulties are too severe. She tries to make herself useful, helping out the staff there as much as possible, by clearing plates and tidying up, however, she can't do as much now as she used to.


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