

# Good days & bad days

Stories of ageing in  
the community

60  
70  
80  
90  
100

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## 1

# Introduction

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Like most developed countries, Britain has an ageing population. Between 1985 and 2010 the number of people aged 65 and over increased by 20% to 10.3 million, almost 17% of the population.<sup>1</sup> Over this same period the number of people aged 85 and over more than doubled to 1.4 million people. With continuing improvements in health care, this trend is set to continue. By 2035 the number of people aged over 65 is likely to account for 23% of the population and there will be over 3.6 million people aged 85 and over, two and a half times more than there were in 2010.

The demographics, statistics and predicted trends can make fascinating, and sometimes alarming, reading. However, all too often researchers, policy-makers, and service providers can become transfixed by the numbers and lose sight of the individual experiences of the people behind the statistics. This report is not about numbers; it is about people. It explores the lives of older people in England today, and of the family and friends around them. We try to show older people's lives in the context of their own personal histories and experiences, as well as their current experience of ageing. How does being older affect them? What are their perceptions of this time of their life? How do their current experiences draw from their own life history? What activities do they take part in? What support do they value? How do they experience support from the State? What would improve their lives?

We have focused our work, and this report, on older people with high levels of use of health services – those who are more frail and vulnerable and it is their stories, in the main, that we tell. However, it is important that we avoid making the assumption that being a certain age automatically entails a particular level of health or independence. We met older people in their late 80s still living completely independently and cycling around town; we met 90 year olds who were out chopping their own firewood; and yet we spent time with people in their 60s whose lives are already seriously constrained by their health and its consequences. We cannot generalise about older people.

This report is written in the context of much discussion of the “ageing timebomb”, rising emergency admissions into hospital, and rising concern about the quality (or lack of) of the care and support that Britain gives to its older people. Much discussion about Britain's ageing population still focuses on the idea of older people as a burden and gives little thought or respect to how much older people contribute to the community, or to their personal narrative. The report aims to give a window into older people's lives, and an insight into the ways they can and do contribute to the community.

The report is also intended to be a resource for use by anyone who is developing services for older people, or indeed developing services for the wider population (given that 15% of the population is now between 60 and 75, and a further 8% are over 75).<sup>2</sup> Our work with stakeholders to date suggests it will be particularly useful to health commissioners and clinicians working within the evolving GP-led commissioning landscape. Although each of the stories shared is of a specific time, person and place we believe and have already seen in practice that they have wide resonance. When we shared one of the stories with a GP from another part of the country, he was struck by how “this story could be about many of my own patients”.

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1 All figures from the Office of National Statistics: <http://www.statistics.gov.uk/hub/population/ageing/older-people/index.html>

2 Office for National Statistics, National Population Projections, 2010-based projections, Table A1-3, Principle projection, England and Wales Summary

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We discuss our findings in more depth in later sections but for us the clearest implication of this report is that 'business as usual' is not good enough even now – let alone for the future of an ageing society. Radical thinking is needed about how we can better support older people within our communities and about how care and support is provided. We need to look both at new models for delivering NHS and social care services to older people, and at how we mobilise the UK's communities to support the older people living in our midst.

## Methodology

This work builds on previous work by the Young Foundation exploring the lives of groups whose voices are less heard in our society.

The primary research method was ethnography. Ethnography is an approach to research that was developed by anthropologists to understand people within their own social and cultural contexts. The primary method of the ethnographer is participant observation, where a researcher spends time with the people they are studying, participating in their lives, asking questions and observing how people act and behave. One of the benefits of this approach is that it forces researchers away from their existing assumptions about people. Rather than going in with assumptions and a list of pre-defined questions, ethnography involves the researcher asking questions in response to what they see going on around them. This allows the researcher to validate what is said with what is actually happening. It can often reveal the discrepancies between actions and words. People's actions and thoughts are dependent on a vast range of factors, and what they say they do in one context is not necessarily what they actually do in another. The explanation participants offer during time with a researcher is often much more revealing than what could be gleaned from a questionnaire or focus group: for example, many of the older people participating in the study shared feelings of bereavement, family tensions and health concerns which were highly personal in nature. We have done our best to conceal the identities of those who participated in our research.

We undertook fieldwork in South London and in rural communities in the South West of England. We spent ten days 'hanging out' with 16 older people, asking questions, listening, observing and participating in what they were doing. Our days ranged from watching test match cricket to singing in local community centres. The older people we spoke to ranged in age from their early 60s to their late 90s. They came from a wide range of ethnic, faith and class backgrounds. Some were single; some were married. We spent time with them alone, and in the company of their carers and family members. All of the people we spent time with were enormously welcoming and generous with their time, sharing their stories, experiences and opinions. We very much enjoyed undertaking our research, and are grateful to all of those who talked to us.

The days we spent with the older people were not structured around a formal set of predefined interview questions. We asked questions in response to what was happening around us and what we were observing. Nevertheless, we were keen to explore a number of specific themes with the older people we talked to. These

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themes included: the system of care around the older person; their health; hospital admissions; recovery periods; use of technology; and mobility and transportation.

We also shared our research findings of this ethnographic research with a mixture of professionals, volunteers and older people in a series of workshops to discuss the implications for their own local services. This report also shares some of the techniques we used in these workshops, which they found valuable to help them think afresh and tackle the issues raised by the research. We believe that at a time of reducing budgets – where the need is do more with less – it has never been more vital to take a different approach in order to translate research into new ideas and action.

## Reading this report

The value of this research does not come from the research numbers – this will never be a representative sample, nor offer a detailed evaluation of each service provider and the support they offer. Instead, the research's value lies in allowing the reader to immerse themselves in the day-to-day reality of these people's lives – using the information to prompt new thinking.

During the days we spent with the older people we were able to observe everything from how they moved around their home to how they negotiated the myriad of services they interacted with. The stories we uncovered make for fascinating and, at times, painful reading. They tell of tipping points that trigger new needs, the importance of family and community and the extent to which older people value trusting relationships and continuity of care. The research also reminds us how much the care provided by older people for each other is a critical mainstay of care and support within the community.

We wanted to share the stories of the people we spent time with in full. We present all ten in detail in Chapter 5 and encourage readers to immerse themselves in each one. Each story is unique and tells of the personal and complex circumstances of individual families. However, similar themes and challenges have emerged from many of them. In Chapter 2 we present an overview of these findings. We shared our findings with commissioners and professionals in a number of workshops and in Chapter 3 we summarise some of the techniques we used (with more detail of best practice ideas covered in Chapter 6). In Chapter 4 we draw some conclusions, and make a series of recommendations for commissioners and service providers.

# Research findings

# 2

Although each story we uncovered was different, there were a number of common themes that emerged from the research. These findings are summarised below:

## Network of Care

**A complex picture:** The older people in the study drew on support from several different sources, and their networks of care were multi-faceted. Many people, organisations and services were involved in caring and supporting older people, varying from statutory health and social care providers to the informal support offered by friends, neighbours and the wider community. Often the most important carer was the (often also elderly and frail) spouse of the older person.

**Family:** Family relationships were, in most cases, very strong. Most of the older people we spoke to said that family members were the first people they contacted in a crisis or emergency, and they saw families as providing significant levels of care and support. However, many families also contained their own tensions, which impacted on older people's lives (particularly if the family member was living in the same house). Furthermore, it should not always be assumed that a younger family member living with an older person is necessarily providing care. In some cases very frail older people were also still caring for and worrying about adult children with serious health issues. We also saw tensions between family members about how much support each was providing to their parents.

**GP and hospitals:** The relationship with the GP was crucial. The GP was very much relied upon for reassurance and information. People valued continuity of care and felt the trusting relationship was built up over time. Many people commented that their GP was best placed to understand the complexity of their situation and all of the different challenges they were facing. Where this relationship was not strong, older people struggled to navigate the care they needed. Experiences of hospitals were varied – from those where older people couldn't fault the care they received to a concerning number of comments about some hospitals which older people saw as places to be avoided at all costs, with poor standards of care.

**Carers:** Several research participants depended on their external carers / social services for support in day-to-day tasks like washing, eating and dressing. Again, recipients of care valued the continuity of care and the building of a trusting relationship. Where continuity was not available, the older people in the research found this unsettling and difficult to deal with.

### The voluntary sector and the community:

Voluntary sector groups and activities were often vital in providing opportunities for leisure activities, socialising with others, maintaining and building relationships within the community and supporting wellbeing, as well as providing practical support and information. This seemed particularly the case in London.

The voluntary sector also had the potential to tap into older people's capabilities and talents. One research participant in South London described how, as part of a local group, she and others have mobilised to campaign against transport cuts. Involvement in the sector facilitates peer-to-peer support; there is a lot of informal sharing of information and advice taking place within these groups and activities.

“

My GP is just lovely and looks after me like gold. She knows all our problems... We can leave a note or a phone call and the doctor will get back us. We couldn't do without the NHS.

“

You would never get better carers. We loved them. We always had the same bunch.

However, participants in the rural community we studied did not consciously identify with the voluntary sector when asked directly. Probing around the topic, we discovered that people were connected to their communities through involvement in cricket clubs, sports clubs, church groups and coffee mornings.

Broadly in the rural area we studied people identified with a geographical community based around a town or village. In London, people identified more with a community of interest (for example, a church group or ethnic group).

**Informal support:** The value of informal support offered to older people by friends, neighbours and the wider community cannot be underestimated. Many of those we spoke with relied upon their neighbours for lifts, and on friends to help with shopping. Relationships with people in the locality – neighbours, shopkeepers, vicars, local police and health care providers – gave older people a valued sense of belonging and connectedness to their communities. The local dimensions of these relationships and day-to-day interactions helped people feel safe and secure, and that support was available when needed. An important aspect of local knowledge was qualitative in nature – in the words of one carer, more than just a directory of contacts – but ‘deep’ knowledge, meaning an understanding of minute pockets of local support which would not be of sufficient scale to get into a public directory. These pockets of support were – in the carer’s opinion – more personal, intimate and richer than the ‘standard’ listed support offerings.

**Lack of coordination:** There are several aspects of the care eco system where lack of coordination between services can cause stress and confusion. Particular issues arose with multiple hospital and clinical appointments, and the challenge of managing so many different appointments and repeating clinical histories and needs many times over. Where someone (whether a community matron, GP, extra-care housing manager or pharmacist) was able to provide co-ordination this was strongly valued by older people. Equally, where services in the community were fragmented, older people found this very difficult. It was noticeable that in the area where our older people were supported by a virtual ward model they were much happier with the community care provided (even although they were not explicitly aware of the model).

Contacting health services via call centres was seen as difficult – participants valued knowing their health professionals and being known by them. People were unclear about how to access to information about their rights and entitlements and many relied on an advocate. Access to the right aids and adaptations remains a struggle.

**Vulnerability:** Many peoples’ situations were fragile. If a family member moved away, if a spouse could no longer drive or if mobility was suddenly restricted people’s situation and needs could change drastically. Older people who relied on their partners, who were often elderly and frail themselves, were particularly at risk. Many of these spouse-carers prioritised the needs of their loved one over their own, and risked neglecting their own health problems.

### Transition points and isolation

Getting old is often characterised by significant life transitions. Many of the people we spoke with had experienced difficult or traumatic transitions – bereavement, serious illness or becoming a carer for a loved one. These events trigger periods of adjustment,

“

We’re not interested in volunteer stuff. We turn to each other first and then to our children.

“

Organising the care for mum is a battle. I had to fight tooth and nail to get this.

“

I need to be with him all the time. He can’t move without me.

“

The stroke, changed our lives. The stroke came out of nowhere and was totally unexpected. One day he was fit and healthy, very active and the next day he had changed completely. It changed everything.

often changing people's lives and situations as well as their needs and the supports and services they access.

Our research highlighted a number of significant transitions: bereavement, serious illness, hospital admission and recovery period, loss of a driving license, becoming housebound, moving house, and becoming a carer.

In many instances such events bring about not just a change in people's material and clinical needs but also create a new set of psychosocial needs. For example, we spoke to research participants who had become housebound after illness, meaning that contact with friends and relatives was severely restricted – resulting in increased levels of isolation and loneliness.

These needs are not always recognised by individuals themselves; articulating emotional responses to life transitions can be difficult. While some service providers recognise these needs they don't always have time to deal with them.

Some of the older people we interviewed (especially but not exclusively those living on their own) were clearly living very isolated lives. They valued time to talk and conversation – but services were often focused solely on meeting practical needs. Loss of a spouse could lead to isolation not just due to bereavement, but through losing the community links a spouse maintained (for example, through a church) and sometimes the carers who had been supporting the spouse.

### Caring for others

We came across examples of older people caring for their partners as well as for children with disabilities. People in this position are often ageing themselves and can sometimes be suffering from ill health, whilst tasks become more physically difficult. This can put enormous pressure on family relationships, causing emotional strain and feelings of guilt.

In one example the caring roles had recently been reversed. The wife was now the primary carer for her husband who had had a stroke. She had sciatica, angina and three heart attacks and he had cared for her; now, after his stroke, the situation was reversed.

Carers often put the needs of the cared for ahead of their own needs and they are reluctant to highlight the challenges they are facing. Respite care was seen as essential, but was often difficult to organise or expensive.

### Mobility

Two people we spoke to had not left their house in a year due to restricted mobility. This causes feelings of deep frustration and helplessness. It also affects relationships with family, friends and the wider community, as well as the ability to access services. Several research participants described feeling lonely and isolated.

In several instances older people were entirely dependent on their partner or spouse to help them get around (for example, by pushing a wheelchair).

“

Every day revolved around her. Every thought I had was around her. I did everything for her in the end.

“

It is another job. I am the only one that can manage him, keep an eye on him. He deals with no one except me. I don't know what will happen when I am gone.

“

You take things for granted. You don't realise until things happen, that you can't walk up the street anymore, that you have taken life for granted.

Changes in people's mobility and movement are often significant tipping points that severely affect people's day-to-day lives and circumstances.

Difficulties with transport were a consistent theme. Continuing to drive (or in some cases at least having access to a car) was seen as very important. Even where public transport was good, on the whole this was seen as too difficult for frailer older people to access. Hospital transport was often found wanting, entailing long waits at a time when older people were at their frailest.

### Housing and accommodation

The research participants we spoke to had different experiences of housing and accommodation, with some living in sheltered accommodation and some living in their own homes.

Sheltered housing was described as supportive and safe. People valued their independence, but felt reassured that support was available if needed.

For those with restricted mobility living in their own can be difficult. For example, stairs and steps can be difficult to negotiate, toilets can be hard to access if located upstairs and adjustments are often expensive. As a result, falls were common.

Many of the people we spoke to had a strong attachment to their homes and wanted to remain living there for as long as they could, despite challenges around access to bathrooms, washing facilities etc.

### Technology

Many of the older people we interviewed were still reluctant to engage with technology. They saw it as something "their grandchildren use" but not something for them. Participants often found it difficult to trust technology.

Technology use was in general very much driven by practical need rather than by wanting to use technology for its own sake (recording TV programmes to watch later, mobile phones to keep in touch when out of the house, landlines or Skype to stay in touch with family members).

Having said that there was some limited use of the internet, with some participants using Facebook and email; one couple we interviewed were enthusiastic users of the Nintendo Wii. Those who did use these technologies found them a really good way of keeping in touch with friends and family who lived far away. Most people had been taught how to use the internet by their grandchildren.

There was a limited use of mobile phones amongst the older people we spoke with. Some used text messages to communicate, but in general people preferred to keep in touch with others through landlines and writing letters.

Use of technology can be physically hard (including mobile phones for people who have had a stroke).

Use of assistive technology varied – for some participants it gave them independence (I can walk round extra care independently); for others it was seen as something they wouldn't use (possibly because it was perceived as being for older people).

“

We won't leave the area.  
It's home.

“

We've missed out on a few family occasions but it's lovely to be able to see the pic on Facebook. You don't feel as if you have missed out so much.

Carers in their 50s and 60s were using the internet to help with care (for example, writing up their favourite memories, care packages, medications and then printing them out and giving them to professionals).

### Death and dying

Many older people spoke openly about death and dying as being something they were preparing for. In some cases people expressed an explicit desire to die. Others were frustrated about the lack of choice around the means and place in which they would die.

“

Death doesn't frighten me; dying does.

### Doing and being

Although many of the older people we spoke to were living with serious illness and frailty it is also important to note how much they were still doing. Amongst this relatively small sample we had examples of cycling, wood-cutting and campaigning amongst people we would typically label as the “old old”. Interests in the external world – in family, sport and current affairs – and letter-writing remained strong even for those who were housebound.



# Tools and techniques

# 3

Part of the objective of this study was to explore which tools and techniques would be most helpful for those who are commissioning and developing services for older people – to ensure that they are genuinely putting older people’s needs and wishes at the centre of these services.

The tools and techniques we share here have been developed around three core themes:

## 1 Sharing stories, sharing lives: getting to a real understanding of the user

As the stories shared in this research show, many of the issues touched upon are sensitive, difficult and challenging. Although there is often value in directly engaging older users in stakeholder workshops or via specific forums, these formats can also preclude real debate and insight. Many people, whatever their age, are inevitably uncomfortable about articulating their most personal and sensitive issues in front of a group of strangers. With professionals in the room, power dynamics can make it difficult for users to articulate their real views, often because people don’t want to complain.

The ideas below are all options which can be used to articulate user voices more effectively:

- Using the ethnographic research stories in the annexe of this report to start the debate. What do your stakeholders recognise in these stories? What experiences are reflected locally? What is different? What are the implications for services?
- Involving older people’s advocates, who can bring along a range of stories to the workshop – it is often a lot easier for participants to discuss someone else’s story than to discuss their own.
- Creating ‘real life’ scenarios as a stimulus for discussion: Role-play can be a powerful tool by which to do this, but workshop attendees are often reluctant to engage with this. An alternative, and often more effective, option is to use role-playing actors within the workshop. Properly briefed (give the actors the full story and background and then ask them to improvise in character) they can challenge stakeholders effectively without all the sensitivities of someone sharing their own life story. This also has the effect of putting delegates back in role, freeing them up to think and comment from a ‘real world’ perspective rather than a workshop perspective. (Local theatre groups are a surprisingly cheap source of actors.)
- Sharing lessons learnt from patients and users of other ages – we found younger patient advocates had similar challenges and concerns which also provided useful insights into older people’s services.

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## 2 Fresh minds, fresh solutions: the use of design thinking to unlock creative minds

Achieving fresh thinking around services, especially in an era of austerity is hard. There is an advantage in using fresh techniques, and avoiding standard presentation methods) to encourage stakeholders to move beyond their usual responses. Some of the techniques the stakeholders found effective included:

- Real time visual minuting. One of the greatest challenges in changing services is pulling in a broader audience to what is happening. Visual minutes (in which a cartoonist makes a real time visual record of the day) can be very effective in achieving this (at the end of one workshop it was felt that nearly everyone in the building had come to see the visuals – a very different experience to sending out a set of traditional minutes!). Furthermore, during the workshop itself the constantly changing image serves to hold the focus of the workshop participants and stimulate debate during interval breaks.
- 10-minute icebreakers at the start of sessions break down barriers between different professions and backgrounds. A quick exercise asking people to find out “one surprising thing” about the person next to them sparked interesting debate on service expectations. Try to make the icebreaker have some connection to the work of the workshop to follow. In a prototyping session we opened with a 10-minute informal exercise where teams competed to build the furthest-flying paper plane. People got to talk to each other in the creative process and at the end of the game understood what prototyping was all about (creativity and experimentation). The paper plane which flew the furthest in one of our workshops was a paper ball, a sure sign that we had freed up some creative thinking space.
- Visioning exercises. Rather than trying to get people to talk hypothetically about a future service we ask stakeholders to describe 5 years into the future as if it were now. There are a range of ways this can be done – writing a postcard ‘from the future’, or drafting headlines from a newspaper 5 years hence. This change in timing is very effective in taking people from the theoretical to the practical. Moving planned ideas into the present tense also helps break down perceived barriers to change.
- Visualising priorities. Move away from the usual methods of asking people for their preference when faced with a list of options. In one workshop we used helium balloons as a voting token: the item with most votes would float to the ceiling of the room, whilst at the same time creating an energising burst of colour.

### 3 Testing ideas through prototyping

The proof of this type of developmental thinking is of course actual change on the ground. Typically after such workshops the response would be to run a six-month pilot of the top idea identified. The risk is that by choosing just one idea and tying down what is piloted straightaway there is little opportunity to iron out operational details. So the core of a good idea can be lost due to issues which could have been fixed at an earlier stage.

Rapid prototyping enables ideas to be trialled quickly on a very small scale. Operational issues can be ironed out and given the lower costs of this approach more ideas can be trialled, making it possible to identify the best option for a fuller pilot. Prototyping in this way often exposes unanticipated issues that might snag a large scale pilot. Examples might be not considering how people might access a service, or potential difficulties with filling in an application form – often small issues, but important ones when it comes to delivery. So, for example, one of our research sites will soon be prototyping a community text messaging service for older people, with the aim of reducing isolation. Rather than moving directly to a full pilot, it will undergo a series of iterations – rapid prototypes – informed by brief periods of experimentation. In this case the process will be to train volunteer older users and a volunteer text message editor, all of whom will be aware that the idea is still being developed. They will use the rough and ready service for two to three weeks before providing feedback at a developmental workshop where everyone will be able to talk about the service from lived experience rather than a theoretical viewpoint. The service will then be changed around this feedback and trialled for a further four weeks. At the end of this short period (just eight weeks), at a very low cost the research site will have a clear view about whether the idea will work in their area (ie whether text messaging is a useful channel of communication for these older people?) and can decide whether to run a larger-scale and more fully evaluated pilot.

#### **PRACTICAL TIPS – WHAT WORKED FOR US:**

It can be very tough getting the right people in the room – especially busy clinicians and social care professionals.

- Shorter sessions work well – busy professionals and volunteers struggle to find time to meet (fitting around clinical and personal commitments). Go for one short focused session initially (3 hours max) with a tight agenda. If the content is valuable, we found people will then make time for further involvement.
- Contact participants by phone before a group session – this gives time to explain objectives, answer questions and address concerns. That way once everyone is in the room introductory work can be kept to a minimum, which leaves more time for real content.
- Get feedback on the session through an online survey (which will save time in the meeting). Using free web tools is a quick and easy way to learn what works best.
- Drive the group and the meeting: if you think the group might be intimidated by an adventurous format, feel the fear and do it anyway. It can't be worse than the usual workshop can it?

# Conclusions and recommendations

# 4

Our conclusions and recommendations fall into two broad areas: First, some lessons for commissioners, clinicians and providers about how they should be shaping their services; and second, some wider policy implications.

## What lessons can commissioners, clinicians and providers take from this work?

### Treat older people as people

Many of the older people in this research described how much they felt they were often treated as just another number. Conversely they very much valued services and staff which treated them as individuals. Discussing this in our workshops, the professionals we worked with commented on how unusual it was to be talking about the person behind the medical or care need – or as one workshop attendee put it, “It is good to talk about the people behind the numbers I deal with.” The older people we spoke to were, by and large, stoic and reluctant to complain – but this did not mean they were happy with the services provided.

#### **Commissioners, clinicians and providers should explore how they can:**

- Ensure development of services is driven by the experiences and needs of the older people who use these services;
- Support older people to articulate what they really want, rather than assuming that lack of complaint means everything is okay;
- Give staff time – and create supporting systems – allowing them to step back and talk to and understand the individual as a whole person, not only individually but also as a person in the community, with values and assets. This approach needs to percolate right through the system, from the design of services to day-to-day interactions. This is what staff were trained to do, after all, and cramping this approach hampers job satisfaction and staff retention.

### Don't assume that “the community” and the voluntary sector are the same thing

Current services often struggle to engage with the community network around the older person. For many older people it is the community (friends, social networks and neighbours) who are their key support network, rather than more traditional voluntary sector organisations. When this informal community network breaks down is when problems arise most rapidly. How the community was structured did vary between our rural and urban research sites, with older people in the rural site being more clearly linked to communities of geography, and older people in the urban site more frequently linking to communities of interest (and struggling if for some reason these links were broken – for example, if a partner died who had been the link to a local church community).

**Commissioners, clinicians and providers should explore how they can:**

- Understand and better exploit the network around the older person;
- Map who provides support from the community before crises happen, so that these support networks are not lost at key transition points such as bereavement, a significant spell in hospital or when an older person stops driving;
- Consider asking older people about their social networks to record alongside more traditional clinical records and diagnoses;
- Look at how they can develop these community networks where they are weaker;
- Engage differently with the formal voluntary sector. Ask the voluntary sector openly what it can do well, rather than coming with a pre-prepared requirement (and similarly, expect the voluntary sector to bring an open mind to the table too). More constrained engagement rapidly leads to disillusionment and both sides putting this into the “too hard” box.

**Support vulnerable older carers**

It was striking how many of the frail older people we talked to were either still carers themselves or had been so in the very recent past. Despite all the statutory, voluntary and community support available, it is older people themselves who still provide much of the care for their contemporaries. Again we saw older carers reluctant to talk about their own health and care needs as they strove to care for a loved one – and, as a result, that their own care needs were frequently not picked up.

**Commissioners, providers and clinicians should explore how they can:**

- Look out more effectively for these carers and support them to express their own needs;
- Consider offering a six-monthly health check up to these carers (it is after all in the interests of the commissioners too that the carers can continue to care).

**Design services to work over transition points - which are a predictable part of the ageing process**

Commissioners should take a long hard look about how services need to change to support older people at key transition points in their lives. These transition points (which can become tipping points into acute or institutional care) can be driven by any number of a range of clinical, emotional or other life-changing events. For many of those we talked to it was clear that these points were “when things fell apart”, and when those who had previously coped stopped coping or lost their independence. Many of these transition points were highly predictable and yet services struggled to meet transitional needs (almost as if they were both constantly occurring and yet perennially a surprise).

**Commissioners, clinicians and providers should explore how they can:**

- Make the unexpected expected for a patient population – and work towards the challenges that their services are expressly designed to cope with transition points;
- Look at models such as virtual ward which are designed to deal with these transition points.

**Improve information provision**

There is across the board confusion about entitlements and services. Information about what is available and useful is still haphazard, with many older people missing out on valuable support. There were frequent references in our research to not knowing where to go for information, or what support was available locally. In this situation the GP becomes – perhaps inevitably – the default source of wider information for many older people. This is not cost-effective; nor is a short consultation the best way of delivering this key information.

**Commissioners, clinicians and providers should explore how they can:**

- Provide advice and information which goes beyond the generic and is personalised and tailored to the individual older person. Develop ways of tapping into the knowledge around “deep” local support, rather than defaulting to a listing directory of standard offerings;
- Think about radical new ways of delivering this information. Start from the standpoint of the older person and work with them to design solutions that they will engage with;
- Give every older person in a patient population their own personal navigator. For the very frail this might be an existing health or care professional. But for younger older people it could well be a trained volunteer or someone who had been “there” a few years ago. This would give every older person an identified person who is “their contact”, and who can signpost them along the journey of ageing.

**Go for the “mid-tech”**

Services currently seem to oscillate between two extremes. At one extreme, there is “no tech” where for example it is often impossible for a carer or patient to email a GP or care provider (whilst everyday services on the High Street easily handle email). At the other extreme, stakeholders aspire to “super-tech” - highly integrated and complex systems on long time-frames. The wider consumer technology context is also changing fast. Technology is increasingly about the user - the iPad is after all ground-breaking in that it has chosen to do more for consumers by offering less functionality. At the same time consumers are becoming more aware of confidentiality and ownership issues around their wider use of technology.

**Commissioners, clinicians and providers should explore how they can:**

- Seek out “mid-tech” solutions making the most of existing technologies such as text messaging and email which are already familiar to families and some older people;

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- Encourage patients and users to own their own data – empowering the older person themselves to decide what they wish to share, and with whom.

### Don't be afraid to try something different

As the old saying goes “if you ask the same question in the same way you'll get the same answer”.

#### **Commissioners, clinicians and providers should explore how they can:**

- Use the stories, tools, techniques and best practice ideas included in this report in development sessions and build up a specific local picture;
- Consider skilling up key personnel in social design methods – these are simple to acquire yet potent in their application.

## What are the wider policy implications?

As well as the issues mentioned above we see two wider issues coming out of the research for policy-makers to address:

- Transport for older people is a major problem in both urban and rural settings. With no one agency responsible for transport and diminishing budgets, older people are increasingly left to fend for themselves. The net result is isolation and a knock-on affect on health, particularly given that getting to the hospital is already a major challenge prior to treatment. Where transport is provided it is a long way from what most of us would regard as acceptable (for example, the story of an older person going to bed in their clothes in order to have any chance of being ready for their hospital pick up the next day). Transport for older people needs to be revisited as not just another service but the oil in the machine which makes so many other parts of the older person's life work (or not). What innovations can be used to improve transport? Is there any role for volunteers in this? Where transport is being funded by the state how can it be organised better? (We wonder whether the routes of our grocery deliveries are more efficiently planned than those of our older people going to hospital appointments...)
- Continuity of care, trust, and the emotional element of a service matter to older people and their carers. For the people we spoke to a key driver of trust was continuity – having the same group of people providing support. There was an understanding it might not always be one person, but what was clearly wanted was a familiar group of supporters (rather than having to explain things anew to a constantly changing cast of care workers, and medical staff). Some of this continuity can be delivered by improved communication, but not all. We need radical thinking to reshape services, and to ask: How do we ensure that older people are supported by people they can come to know well rather than being asked to fit what the system can offer?

# Ten stories of growing old

# 5

## 5.1 Tony's story

Tony is in his late 70s and has been living in the same house in South London for the last 42 years. "When we moved here it was more middle class. But we've had an influx of people come in...The only people left of the old guard are me here and Beryl next door." His wife died two years ago after a long illness, and Tony now lives with his son.

### Background

Tony spent much of his young life with Barnardo's. "My mother went away with a new bloke and there was no room for me." He remembers this part of his life as being very tough: "When I was in Barnardo's we only had shoes for 2 months of the year in January and December. The rest of the time we were barefoot." At 15 he says "I had no choice but join the navy. I had to leave Barnardo's."

Tony moved to the South Coast initially and then he travelled all over the world with the Navy – "I went everywhere. The Med, Malta, Norway." Eventually, Tony left the Navy to settle down with his wife Anna.

After the Navy, Tony worked for several years with a large cleaning company. "I started cleaning the floors in a central London office block. I made my way up to senior manager. I worked hard to get there. I did well."

He talks proudly of the work that he was involved in and the experiences he had. "We had all the big contracts in Lloyds, Lambeth Palace and Buckingham Palace. I really got to see it all."

Tony retired some years ago. "They made everyone retire at 62. I wanted to stay on. I had good relationships with my colleagues. I made some good and loyal friends. One of my best friends was my foreman." He talks fondly of the friends he made while working; he tries to keep in touch with some of them by writing letters and phone calls.

Tony has numerous children and grandchildren, some of whom live abroad; others are scattered across the UK. One of his sons lives with him which provides reassurance that someone is in the house. Tony loves seeing his family when they can come to visit. "They come as often as they can but it is expensive." However, there are also family tensions about how often different family members visit, and how much each member of the family helps out and supports Tony.

### Bereavement

Tony's wife Anna was originally from continental Europe. She was evacuated to Eastern Europe during the war after her parents were killed. After the war she came to work in the South of England as a teacher. Then she got a job in local hospital and trained to be a nurse. "I met her dancing in the Astoria, Charing Cross Road and it really was love at first sight. She was a stunner. We both loved dancing." Tony says that he and his children "miss her every single day but I know she's looking down."

Before Tony's wife Anna died she had been very ill. She had cancer and dementia. Initially she was cared for at home by Tony, with support from carers. But her situation steadily declined and she could no longer stay at home. She was moved into a care home. "We tried to keep her at home but she was incontinent and she fought." On one

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occasion when Tony went into hospital Anna went into a care home and didn't return home again. "She had senile dementia at that stage and she was having little strokes going up to the brain."

"I went to see her every day unless I was in hospital myself. I used to bring her home every Saturday in the car to get her out of the home."

She also suffered from cancer and had several operations to treat it. "It doesn't seem fair that it ended like this. She devoted her life to the children. She brought the children up and they all got on well."

His wife's ashes are still in his bedroom. "She is on my mind everyday and everyday I wish she was here with me."

Tony had a memorial bench for his wife put in the nearby park where they spent a lot of time together. "I can't go there but the children and grandchildren go up now and again."

## Health

Tony suffers from numerous health problems. He has diabetes; emphysema; angina; he has arthritis in his back, hips and knees; he has had a hernia operation and after he retired he had a triple heart bypass. He says that one section of his heart "doesn't work".

Tony takes a lot of medication. The pharmacy is close by and Tony has a good relationship with the pharmacist. "I know the pharmacist, Peter. He gets the prescription, sorts it out and delivers it very quickly." Tony takes tablets four times during the day, a total of 40 tablets daily. He has a case downstairs with a mask that "looks like something out of 'Silence of the Lambs'". I think it is to help me breathe but I am not sure". He is supposed to wear it when he sleeps but he "couldn't get used to it".

Tony's arthritis causes him considerable pain and mobility problems. "If I could get rid of the arthritis, life would be easier but we have got to make do with what we got. There is no use moaning."

He attends the pain clinic on a regular basis. "Sometimes they tell me pain is imaginary. That works if you only have one thing wrong with you. But with me it's my knees, my back, my thighs. It's everything."

He was recently in hospital for an epidural to ease some of his pain. "I feel like a different person after the epidural. I can see how people are addicted to morphine. It deadens people."

He has a board on the wall with all his hospital appointments and clinic appointments. His carer helps him sort it out. "All of the appointments are very confusing." Tony says he can often wait a long time for appointments to see specialist doctors and consultants.

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Most of the time hospital transport is provided for free but these visits can still be challenging experiences. When Tony has pain clinic appointments they are usually early and he has to get ready by 5.30 am. He has to be ready two and a half hours beforehand to be ready for transportation. "I go to bed with my clothes on. It is easier waking up dressed." Tony dreads this. "You have to eat beforehand because you are diabetic. Then you have to wait a long time, up to three hours to go home."

He finds the whole experience very stressful and tiring: "The last time I was there I got nothing but a cup of tea and I told them I am diabetic. They are very disorganised. Eventually the nurse got me a sandwich....12 hours later I got home. I was totally knocked out and after that I didn't sleep well."

Tony says he has "periods of going into hospital three or four times in a couple of weeks and sometimes less." He visits several hospitals around London. "I am blessed. I have been treated by the best doctors in the world. They really are very nice. They care. You can sense they care."

### Coming out of hospital

Last year Tony spent six months in hospital on and off. "I don't want to go into hospital again. I am just interested in getting home when I am in hospital. The last time I was in hospital I couldn't eat anything."

When he was discharged he went to a respite centre. "It was great. You didn't have to worry about the appointments, they come to you." Eventually Tony returned home but the community matron thought he was still in hospital. Tony says that she wasn't told by the district nurses that he had been discharged. "There were some terrible crossed wires. I know they are very busy but they don't want to know."

He has difficulty remembering this time clearly. He was in incredible pain. "I was on lots of morphine. I can't remember it very well. But I cut the morphine down myself. I don't know how anyone could stay on it."

### Community health services

Anna and Tony used to go to a local GP and had the same female GP for over 20 years. That surgery has since been knocked down to build a DIY store. Tony feels that the new surgery is too big and they have taken on too many patients. It is now very difficult to get an appointment with the GP when he wants one. "I call the surgery a lot but you can't get through on the phone."

Because of his mobility problems Tony finds it difficult travelling to the GP surgery and would prefer a home visit. "I haven't been to the surgery in a long time. I am almost housebound. I depend on someone else to get out." But it is often difficult to arrange a house call. "Nine times out of ten they don't do a house call - they will only do a phone conversation. I don't dare ask for a housecall sometimes. I know I will be told to do a phone call. But when you are not feeling yourself, you're not feeling up to it can be just too difficult."

Tony sometimes feels that he doesn't get the personal care and attention that he needs. He isn't happy when he gets an appointment with a different doctor. "My case is complicated. My own doctor knows my case. I shouldn't have to repeat everything."

He also feels frustrated when he can't contact the district nurses: "You should be able to get in touch with them much more easily than you do. I used to be able to phone up. Now I just get put through to a call centre. You must call an operator or a call centre and sometimes the line goes dead." These experiences make him feel like he is not "an important patient as far as they are concerned".

However, Tony has a lot of praise for the community matron, Mary, and his relationship with her is key to overcoming some of the challenges he faces with other services. "She is very good, you couldn't ask for better. I must be a bit of nuisance but she puts up with me. I wouldn't get by if it wasn't for her."

Tony says he gets good care and advice from Mary; she helps him find out information. At the moment she is helping find out where he can get a new bed. When he came out of hospital after his bypass he was supplied with a hospital bed. But that was some time ago and it is uneven now and he can't sleep.

Tony is quick to point out that he doesn't want any hand-outs: "Some people demand and they think that they are entitled to everything. But you are not entitled. You have to go through the proper channels."

## Care and finances

Tony says he feels very lucky that he is financially secure. But Tony still feels stretched financially sometimes. The occupational therapist told Tony that he needed a ramp for the steps at the front door. It would cost £12,000 and Tony is not eligible for any help. "They tell me I have too much money. It's so wrong I have to pay for everything. I am well off but sometimes I feel like it just disappears and I don't know where it goes."

He doesn't know how long he has had a carer: "Maybe a year? I'm not sure." According to Tony, the council said that he needed a carer and that it would cost him over £25 an hour. "Someone told me to go private. And I found a company that I had to pay £13.50 an hour."

He tells me that his carer is not called a carer anymore but now she's called "support". "I insisted on Stella because I had her for a trial and she was so good. I had other carers who were dirty and scruffy, the other one smelled of alcohol."

Stella comes in the morning for an hour to help Tony out of bed and dress the bed. She does some laundry and washing up downstairs. Sometimes she will bring him some toast and checks that he has taken his medication. "She makes sure I am showered and helps me get ready for the day." Sometimes she takes him out to a couple of the shops. He likes to go to the Marks and Spencer's in Croydon. They take a cab and he pays.

He has asked if Stella can come 2 hours a day. She is waiting for her supervisor to clear it. Tony would like if she could spend a bit more time with them. If there is nobody around Tony spends a lot of the time napping. "That isn't good for me. I would like some companionship, somebody to talk to. Not just about the serious stuff but what's on the television and the news."

A cleaner comes to the house twice a week. She comes for two hours on a Monday and Friday. She is a family friend lives down the road. Her husband sometimes comes with her "for a chat".

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Tony would like to be able to do more about the house and he tries to do as much as he can. "I try to do the ironing myself but sometimes the cleaner does it."

His son and granddaughter come every Sunday to visit Tony and to do his shopping in Sainsbury's. Sometimes Tony goes with them. "They come and make a list and see what I need." Sometimes they go out for lunch "but we haven't done it in a while as I haven't been feeling up to it".

Tony tries to cook for himself as often as he can: "I like cooking but I don't do it every day. Yesterday I cooked some cauliflower, Yorkshire pudding with meat and carrots." If he doesn't cook he has some ready meals; his favourite is fish pie.

He has a small fridge and a special machine for heating water beside his bed. This means that he can make tea, coffee and instant soup without moving. His carer recommended that he use plastic cups. He could just put them in the rubbish without taking them downstairs. "I can't move around the house much so it makes sense." His son buys snacks that he can keep in the fridge, like scotch eggs and cold meats.

## Mobility

Tony's mobility is severely restricted. He can't really move one leg. He can't move around the house without a walking frame and even then he moves very slowly. He can only go downstairs using the chairlift. When Tony goes out he has to be in a wheelchair and so he needs someone to push the wheelchair. "I bought [a wheelchair] because I had been waiting so long."

Tony says having that having the walking frames upstairs and downstairs are very useful. He had several falls before he started using them. Tony has also fallen out of bed in the middle of the night a few times recently. His son had to come in to the room to help him back into bed. "If he wasn't here I would have been on the ground all night."

The steps at the front door are also a big problem for Tony. He can't afford a ramp and he has to try to walk out with two sticks when he is being transported to hospital. "If the ambulance men are strong enough they lift me ... A scooter would be ideal for me. But I can't get it into the shed outside to charge it and it can't get through the front door.... But I don't like moaning, I know there are worse off than me."

Tony can't drive at the moment but he is very attached to his car and feels secure having it. His son who lives with him sometimes drives the car to take him to hospital. His neighbour sometimes drives Tony if he wants to go somewhere, but he will ask for payment. "If the car is there I feel better. If there is an emergency I can be taken out. Someone can use it ... I don't want to drive. It just gives me a sense of security. I would like if there was someone else who could drive me. It's the only way of getting around and it is causing me a lot of stress and worry."

## House and home

Tony lives in a three-bedroom, two-storey terraced house. Recently someone from social services visited Tony and suggested he move into a ground floor flat. "You've not going to move me. No way I said. I am here over 40 years. Nothing will move me. I'll be here until I die."

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Tony says he is very happy where he is even though he has seen many changes in over the years. "There has been a lot of change on the street, people coming and going, renting, you don't know who is around the corner. I can't keep track."

There have been several adjustments made to the house to help Tony cope with his limited mobility. There is a chair lift on the stairs. The bathroom has been adapted so that the bath is easier to use and there are several 'perching chairs' situated through the house, which are easy for Tony to sit in.

Despite the changes, Tony still spends most of his time upstairs in his bedroom. "The TV is on most of the time. I usually wake up at around 6 am and I watch TV for a bit." He likes to listen to CDs sometimes. One of his daughters gave him some meditation CDs that she thought would help with his pain.

There is a cordless phone with large red buttons on his bedside table which he uses a lot. There are two cordless phones downstairs also. "A lot of things I have to phone up about. The car, the pharmacy, appointments. It's my lifeline."

He has two mobile phones. He thought one was broken so he bought another one. "I never use them. I only used it when Anna was alive. Sometimes I take a mobile to hospital but I sometimes I forget."

There is also a special place in his bedroom for an urn containing his wife's ashes. The urn is surrounded by fresh flowers that he replaces every Sunday when his son and granddaughter go shopping. "I want to be reminded of her every day."

Tony says he usually only goes downstairs to prepare himself some food or to go on Skype to talk to his family abroad. It takes him about 10 minutes to get downstairs to answer the door if he is on his own. He has a camera installed near the front door so that he can see who is there. People can ring the bell and he can see who is there he won't answer the door unless he know who is there.

He is very security-conscious. There are stickers on the door: No callers unless by appointment and We don't buy anything at the door. "People are calling all the time selling double glazing." Tony tells me that he was recently scammed and he was very upset by the experience. Tony called the police reluctantly but they couldn't do anything.

## Social life

Work dominated much of Tony's adult life and he says that he didn't really have time for much else. "I don't really do that much. Even when I was a fit man all my energy was put into working. I was a workaholic apart from the church." Tony's wife and children were very much involved in the local Church of England, but since she died he has lost touch.

He would like to find out more about local organisations but he doesn't know where to get this information. He says there is a community centre up the road and he has seen older people going there to have lunch. "I can't get round to the voluntary groups. That's the problem. I don't know what is going on. When I go up to the clinic I see older people having lunch there. I don't really know what it is. I would like to join. But I don't know who to ask."

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Tony also says that getting out and about is very difficult, as he needs someone to push his wheelchair and he needs to use a disabled toilet. “I would love to go to the coast. If there was a group organising something like that I would love to join. But I have problems. I need someone to push my wheelchair. Going to the toilet is difficult. It’s a problem.”

### Technology

Tony bought a laptop but he can’t get used to it. “I wanted to try it out.” One of his sons abroad “tells me what buttons to press”. He has an account on Amazon and with Marks and Spencer’s online “to buy underwear and socks”.

His son who comes on a Sunday buys things online for him. Tony uses Skype every Sunday morning to talk to his family abroad. “I know how to get on Skype by myself. I really enjoy seeing my grandchildren. I hear their news. It’s great. They are all using Facebook, but I don’t know what it means.”

Despite his enthusiasm for technology there are some things he has found it difficult adjusting to: “I am supposed to be using online banking but I haven’t a clue how it works. My daughter set it up but I am only using the hole in the wall.”

### The Future

Tony he says is happiest when he is not in pain and when he is spending time with his grandchildren. “I would like more days like that.” Tony would love to be able to leave the house about any more. “I miss seeing people and getting around London.”

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## 5.2. Margaret and John's story

### Background

Margaret, in her late 70s, and John, in his late 80s, live in a three-storey, terraced house in South London: "We bought the house in the late 1960s for £6000. Can you believe it? It was a lot of money back then." The couple are Anglo-Indian and came to the UK from India in 1965 because "we didn't fit in anymore in India and we wanted our children to have the best education, the best opportunities in the UK".

### Family

After her parents' marriage ended Margaret was brought up by her grandmother. She is an only child but she has a number of step-siblings, some of whom have passed away but the rest of family are still in India. She calls them all every Sunday morning and "we have a long chat. I want all the details". The couple use the landline a lot and their phone bill is very high.

John has four siblings and three of them have already died. He was particularly close to his older brother. "I try to keep the connection." He has several nieces and nephews who are still in India.

The couple have a large family (children and grandchildren). Many of the family live and work abroad in the US and Europe; one son is currently living with them. They speak proudly of their children's achievements (a number are now working in the professions), but also worry about one family member who has serious mental health problems. They have visited their family abroad but now they find travelling too difficult and the children mostly come to visit them, rather than the other way around. Their US family are all coming to London in a few weeks to belatedly celebrate Margaret's birthday and they are both very much looking forward to this family gathering. "We can't wait. We have been preparing the party for months."

### Work

When Margaret first arrived in the UK she did a few cleaning jobs. She then applied for a job as a clerical officer with a large communications company. She worked there for 23 years. Initially, she worked in the finance and accountants departments: "I loved maths, I loved numbers." She then progressed to the planning departments. "I loved every minute of working there, great people. I worked in several departments and moved up the ladder. It was always interesting." John found moving to the UK harder. When they arrived he got "odd jobs in factories" but found the upheaval very difficult. He became quite ill soon after arriving in the country and had "trouble with his heart". He also has diabetes. After his "heart trouble" John gave up working completely.

For many years Margaret balanced her career with bringing up her children and caring for her son and husband: "I was going non-stop looking after the children, looking after my husband, taking care of my mentally ill son – it was another full-time job but I was focussed. I had to be the strong one."

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## Health

As well as his heart problems John has only partial vision and is very hard of hearing. Communicating is difficult and he lets Margaret do most of the talking. He spends most days resting in bed until the afternoon. He says he has “always had a weak heart”, and that he has had “a couple of heart attacks and had a pacemaker fitted years ago.” Margaret says her husband is “just surviving. But I am looking after him. I always have done. I take I him everywhere I go.”

Margaret has had her own health problems since she retired. She has diabetes and chronic kidney problems and a couple of years ago she underwent a quadruple heart bypass. After this operation she was “very, very sick.” Her daughter who is a doctor came from the USA to be with her during this time. This was extremely helpful: “She helped us understand what was going on. It was a terrible time.” Her daughter also helped in communicating with a vast array of medical professionals that Margaret was coming into contact with. The whole experience was very difficult for Margaret: “It was trauma. I couldn’t walk. I couldn’t eat – not even soup, just Bovril.”

## Recovery period

After her bypass operation Margaret went to a convalescence home by the sea for a few weeks and then returned home. When Margaret came home she wasn’t supposed to do anything. “I was helpless and I relied on [my daughter] for everything.” But her daughter soon needed to return to the USA.

This was a scary time for Margaret. She felt very weak and she was “frightened her mind would go.” She and John depended on a ‘meals on wheels’ service and they were very pleased with this at the time. Social services sent carers to look after them. At first they came every day to help with bathing and getting in and out of bed. They also helped with housework. Margaret was not happy with this set-up: “It was very disgusting. They weren’t good at what they were supposed to be doing and there were different people coming all the time.” The couple found it difficult to establish a trusting relationship with them because of this lack of continuity. It was also quite time-consuming as they had to explain their situation over and over again to new carers; what they needed and where things were around the house.

They also encountered a language barrier. They had carers from various countries and there were problems with understanding each other. “I didn’t like it. We were home alone with these strangers. Sometimes I was scared of them. I don’t want any Tom, Dick or Harry coming in.”

Margaret had a lot of hospital appointments and depended on the carers to help her coordinate these visits but sometimes they didn’t come at the designated times. This was often very upsetting and caused chaos.

Margaret was on a lot of medication which often made her drowsy and sleepy. She describes herself as “not with it”. On one occasion her cheque-book went missing and Margaret suspects that one of the carers might have been involved. On another occasion a carer’s husband turned up unannounced with keys to the house. Margaret contacted social services to complain but nothing was resolved conclusively.

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After a couple of months Margaret and John got so frustrated with the situation that they contacted social services to cancel the service. “It was a complete waste of money. We weren’t happy.” They decided to make their own arrangements.

Through their church she found someone they felt would be appropriate: a man named Roy, originally from the West Indies who is autistic. “He helps us with odd jobs around the house, painting, DIY, a bit of cleaning, going to the post office, collecting things from the pharmacy.” Roy has now been coming round their house for a few hours every Saturday and Sunday for the last six years. “He is part of the family. He cares for us and we care for him. He doesn’t talk a lot but that doesn’t bother us. We get on.”

They don’t have any interaction with social services at the moment: “We don’t take anything from them. We pay for everything but we get a better service.”

### Support network

Between them, Margaret and John estimate that they spend “at least one day a week going to hospital and doctor appointments.” In addition to visiting her GP regularly, Margaret goes to see the heart surgeon every six weeks; a specialist heart nurse every few months; a diabetes nurse from time to time; and a specialist doctor for her kidneys. John visits a consultant for his heart regularly as well as the diabetes nurse.

Margaret and John both take a lot of medication. At the moment Margaret is taking 14 tablets in the morning and five tablets in the evening. Her husband takes less. They both manage their own medication. Her husband takes tablets for his diabetes but Margaret must give herself an insulin injection every morning.

Margaret has regular contact with her GP whom she describes as “lovely, she looks after us like gold”. They both consider their GP as the most important person caring for them. “She knows all our problems, she communicates well. We can leave a note or a phone call and [the GP] will get back to us.”

They have gone to the same GP practice since they moved into their house and the continuity of care is very important to them. “The doctor knows us well. She is not just reading off notes. The nurses know us there also.” Margaret says that she will only see “people she knows and not anyone is good enough. I will ask for the person I want. I don’t care if they are on the golf course.”

There used to be a diabetes morning at the surgery where the nurse gave advice and information, but funds for this service have now been cut. However Margaret and John remain positive about the health service and the standard of care they receive. “We couldn’t do without the NHS.”

### House and home

Margaret and John have lived in the same house since the late 1960s. They know the area and feel very much at home there. “We won’t leave the area. It’s home. We know our neighbours enough to say hello and goodbye.” But the area has changed a lot since they moved in: “It is so much busier and there are lots of people moving in and out. We used to know everyone but not anymore.”

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Their house is spacious with three storeys and four bedrooms. Margaret is in charge of household affairs and she “takes charge of the paperwork.” She has set up direct debits for the gas, heating and telephone. She is quite organised and keeps track of hospital appointments and contact details for their various doctors in a large diary. She does this for both herself and her husband.

She also does the laundry, cooking and some cleaning. She really likes cooking. “It’s my favourite hobby.” Their carer does some of the more physically demanding household chores – like changing the bed linen, hovering and ironing. There is a small garden area at the back of the house with some plants but they find it difficult to tend to as it requires bending down, so “Roy tries to look after it.”

There are lots of leaflets on the tables and on the noticeboard about information meetings for older people, information sessions at the doctor’s, information about diabetes and hayfever. Margaret says she always picks up leaflets wherever she goes and will read everything. That’s how she finds out about things and if things are changing.

The house is over a hundred years old and needs some maintenance. Some of the work that needs to be done is quite expensive. Recently they have had three builders in for a week doing repairs. They cancelled all their appointments for the week so that they could stay in the house while the work was being done.

Margaret found the builders through an advertisement that came in the post. She knows that older people are getting conned all the time through various scams but “you have to trust people sometimes.” Her daughter was worried about her parents being on their own with the builders but Margaret says she is very security conscious. She keeps everything locked and keeps valuables hidden away. They are also involved in Neighbourhood Watch.

## Travel and mobility

Margaret and husband used to travel abroad regularly and they visited the USA and India a lot. When Margaret retired they went on a round the world trip, “We had the time of our lives.” The entire family also went on holiday to India a couple of years ago. Their carer Roy also came. “It was a special time being all together.”

But because of their heart problems air travel is no longer possible. They accept this but Margaret would love to go on more day trips to places like the South Coast. A local voluntary organisation used to organise trips like this and she and her husband really enjoyed going but for some reason they stopped. “They said they had no money.” Travelling is also difficult because Margaret and John are both diabetics, so they have to be careful of food. Because of Margaret’s heart condition she is also restricted in terms of what she can eat; spinach, grapes, bananas, or anything else with high potassium is out.

Travelling around London on public transport has also become very difficult. They find moving about in public areas and streets very difficult and stressful. They are often fearful they will be run over. “You have to take care or you will be trampled on.” Margaret describes her experience of falling on the bus as ‘terrifying’. When she fell she broke her glasses and couldn’t see. She also injured her knee very badly and had to have major surgery and parts of her knee replaced. She needs a walking aid and

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only really feels comfortable walking about indoors at home now. Before her fall, she says: "I was a gadder –never stood still but that's all changed now."

Margaret and John feel comfortable moving about at home even though this can be difficult too. Margaret fell at home recently and she couldn't get up for some time. There was nobody around to help her and she was groping around on the ground for thirty minutes before she got up.

There are several steps even on the ground floor of the house. Their sons installed some bars to help them get up and down. Margaret and John are determined not to be defeated by the staircase leading to the other floors but Margaret does say that it can take some time. Some days John may not come downstairs at all if he finds it too difficult.

They have a lot of hospital appointments. They used to have a couple of options to get to them to their appointments but due to funding cuts their only option is to use an ambulance. Margaret doesn't like this as she feels like there are "worse people off than [her]." Her daughter sometimes helps by taking her to hospital when she visits.

Margaret has put a lot of energy in campaigning for the return for some of the transport services and has gone protesting outside the local council offices. She says that she knows a lot of older people who have really felt the loss of the service. "If you don't shout you won't get anywhere. If there is something to complain about I will complain." She has been complaining, campaigning and writing letters to the local council and her local MP. She was also involved in organising a petition. Margaret recently attended a meeting about transport for older people in the House of Commons. She is hopeful that her efforts will pay off.

## Social life

Margaret and John are involved in a wide range of activities and there aren't usually at home for the whole day except at weekend. "The only reason I am at home today is because the builders need me to be here."

Most days she has something scheduled. Monday is usually the day she and John arrange their hospital appointments; Tuesdays they go to the day care centre for exercise, baking and gardening. Margaret has also taken it upon herself to organise an older people's forum at their local community centre. "We get together, drink tea, get ideas off the ground and write strongly worded letters." On Wednesday's she goes to another day centre (not in her borough, but there is a special exercise class that is helpful for her knee). Every other Wednesday she goes to the carers' hub for a coffee morning; on Thursday her ill son comes round and she supports him; on Friday she goes to another local club for the elderly where she sings in the choir; on Sundays they go to church together.

They go to the church around the corner. Religion and the church community are very important to them. Their religion gives them "strength and inspiration."

Margaret says the spending cuts in the local area are impacting older people. Lots of services, particularly leisure activities have been cut. "So many clubs are closing. I don't know what older people will do."

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Sometimes they invite local councillors to the meetings if they are trying to address certain problems. Margaret says “the councillors come to talk a lot but say nothing.”

Margaret admits that she is the driving force behind most of the activities. John enjoys going but sometimes he just “needs to rest.” Other times he takes himself “around the corner to the church for a bit of peace and quiet at lunchtime.”

It's clear they both enjoy going to the clubs. “It's getting out of the house to mix and meet with people and see their friends. It's a chance to listen to others, people help each other out and it is a good chance to share information.” Margaret feels that at her age “it's important for people to hear happy news too.” They often organise have parties and celebrate each other's birthdays and special occasions: “It's like a family at the clubs.”

A lot of the older people are not happy with the quality of the food and drink at one of the clubs that Mary attends. So she has called a meeting together for next week where she will ask the cooks to taste the food.

## Technology

Margaret and John use the landline every day. They don't use email and they don't have a mobile. “We don't bother with that.” The couple's children and grandchildren all use email, but Margaret says she prefers “personal contact” .

Margaret and John's children would like their parents to get a mobile phone but she “can't be bothered. Technology is fine for other people.” She describes mobile phones as “a pain in the neck, you never have a quiet moment with them” .

Margaret takes care of all of their banking over the phone or sometimes their carer accompanies them to the bank. Margaret is happy using telephoning banking or writing. They don't use their bank card as they are afraid that someone else might use it.

The pair watch a lot of television (freeview) and listen to the radio. They like watching the news and the soaps. Of course, they watched the royal wedding together. They made sandwiches and two of their friends from the day centre came to watch it with them.

Margaret has several pen pals that she writes to regularly in India and America. She makes telephone calls to her pen pals also – usually Christmas, birthdays and anniversaries.

## Views on ageing and care

“Old age is painful. It's all problems. All problems,” according to John. Margaret has a different view. “If you don't use it, you lose it,” Margaret says and this is her motivation for being involved in clubs and activities. She is very critical of care homes and day care centres. She hates seeing people sitting in corner and watching TV, without an incentive to do anything. “They wither away.” She is also critical of the people who work in care homes particularly the managers. “They always say they are too busy to do anything new.”

She thinks that older people in homes need more stimulation. "It doesn't matter if you hands and legs go, your mind isn't gone." The carers in these homes don't do as much as they should. "They don't inspire, they don't improvise and they don't give any incentives to older people." She has heard from friends that they do just the minimum. Margaret wonders about the level of training about a lot of them and says that she will do her utmost to make sure that they don't end up in one. "We eat the right food, we have a nice house and a good family. We get by ok."



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## 5.3 Maria's story

### Background

Maria is in her early 90s and lives with her daughter Pamela and Pamela's husband Simon, who are her full-time carers. Maria suffers from multi-infarct dementia, diagnosed in 2006. In 2009 Maria experienced a mini-stroke and her condition has deteriorated over the past three years. She is unable to walk without assistance; she has difficulty communicating, is doubly incontinent and has very poor memory. She is largely oblivious to what is going on around her and spent much of the day we were with her nodding in and out of sleep in her armchair in front of the television.

Maria was born in the early 1920s in a small farming village in northern Italy. She came to London when she was seven and her father worked delivering blocks of ice from a factory in South London. She had a younger sister (who died of cancer in 2001) and a younger brother. Maria left school and became a waitress in a café that her father had opened. She continued to waitress in family restaurants until she retired at 65.

Maria met her husband David while he was a prisoner of war during WWII. They married in 1947 and her husband joined the family catering business. They had five children, and many grandchildren and great-grandchildren. David died in the mid 1990s. Maria moved from the family house in South London to a smaller house in order to be closer to her children who lived locally. The house is a comfortable 1930s semi-detached property. Pamela and Simon moved in to help care for Maria. The family appear to be relatively comfortable, although by no means wealthy.

"It's a nice area apart from the muggings and murders. Someone was stabbed up the road. For that reason I switched Mum's pension from the post office to the payment into her bank. It was a shame as it was something she enjoyed going to get, but what can you do?"

### Health

Until about five years ago Maria was able to live independently with some help from Pamela. Then she was diagnosed with multi-infarct dementia and suffered from a mini-stroke. She also suffers from hyperparathyroidism (producing too much calcium), hypertension (high blood pressure), osteoarthritis, recurrent urinary tract infections, arterial fibrillation (irregular heartbeat), lower limb lymphoedema (swelling of the legs and feet), and a type of eczema. She is using the drug Warfarin following her stroke.

"Mum's oblivious to what is going on around her. There's been a gradual deterioration in her condition over several years; since her stroke really. It's Mum, but not Mum – if you see what I mean. Her shape and form, but it's not her. If you'd come 10 years ago, you won't have lasted this long in the house without being served a full Italian meal. 'Have you eaten?' would be the first thing she'd ask anyone. She'd go away and knock up some pasta or something. She hasn't cooked for the last 6 years. It's not her."

"Mum's GP is fantastic. I can do nearly everything over the phone. Mum has regular urinary tract infections. I can use the dipsticks at home and take samples and then drop them off. The Warfarin was a problem. You can't do that at the surgery, I had

to go to the hospital. Because Mum is on and off antibiotics all the time, the amount of Warfarin changes. Going to the hospital every time with Mum is a nightmare. Transport, all that waiting about. It makes her worse. I thought there must be a better way of doing this. I invested in a machine so I could test her blood at home. It was the best £400 I've ever spent. I take a drop of blood, tell them what the INR result is over the phone and they tell me how many milligrams of Warfarin she needs. They send the label in the post and I put it in the yellow book."

### Care eco-system

Pamela, Maria's daughter, is the primary carer. Pamela looks after her mother every day. She used to be a professional carer, but gave up her job to look after her mother. Although Pamela is a former professional carer and clearly knows her way around the system, her descriptions of her interactions with private and public care providers are scattered with the language of conflict. She describes having to fight for access or information, having to stand up to social workers, and having to complain at every stage. Pamela describes organising the care for her mother as a battle. "I had to fight tooth and nail to get this."

Pamela is well informed and feels she has built up an awareness of what she and Maria are entitled to in terms of care and benefits. In many cases she feels that she is better informed than some of the staff working for the organisations or institutions. "Someone from DWP came to visit us to review Mum's pension. I said, 'I assume you know about Mum's pension?' 'Oh, I left the forms in the office.' So I gave them a copy of the papers and asked what else she was entitled to. 'Er, I don't know.' 'What the higher rate for attendance allowance?' 'I don't know.' They didn't know what was going on. God knows what other people do."

While Pamela provides most of Maria's care, she also receives support from a range of public, private and voluntary organisations, providing regular personal care and an occasional sitting in the home service, time at day care, a lunchtime club that Maria attends and respite care through private care homes (the family pays top up fees).

Pamela explains that there is a considerable difference between the public and voluntary sector. "The social services attitude is to say no. The voluntary sector approach is to say let's see what we can do."

"Social services and the NHS are only concerned with cost. Not the people who need the care." Pamela says that she feels pressured by social services to adopt a "personal care budget or whatever it is called. I would have to organise the care package. Paying a fee, tax, National Insurance. I'd have to find someone and what if they get sick. If you use an agency then they can send someone else. I'm sure it works for some people. I don't know how they work the budget out, but it would be much more hassle for me, more stress, I'd have to advertise, interview a person. Do I need all of that on top of this? I don't want the stress and strain of having to employ someone. Social services should up the care package around us."

As Maria's condition has deteriorated, Pamela has found herself coming under increased pressure to put her into a care home. Pamela doesn't want this as she doesn't feel that the care homes provide high enough levels of care. "If she goes into a home I might as well sign the death certificate now. Whenever she goes in for respite, she comes out in a hell of a state. The last time she was in respite, when did she fall

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over? At night when she was trying to go to the loo. I told them that Mum has to get up in the night. They said she had already got up once, but you have to make her cough to full empty her bladder. If you don't she's up and down all night."

Pamela's biggest complaint and worry is the poor levels of care that are delivered by staff in hospitals and care homes. "I hate hospitals. They have no concept of how to look after someone like Mum. Even in the geriatric ward. You'd have thought that they would have the specialist skills and that. But no – the young nurses have no idea of the caring side of their jobs." Pamela complains that the nurses are moved around between different wards and are not necessarily interested in working with older people. "The same is true in care homes. We don't use the local authority ones any more, they're awful. But even the private ones are disappointing. £1,200 a week. We told them all about Mum's care plan, but they didn't take any of it on board. We want her to take part in activities, but they would ask if she wanted to do this, or wanted to do that. She'll say no every time. You have to say 'we are taking you downstairs for bingo.' You have to tell her. For £1,200 a week you don't expect to be left in a chair in front of the TV. They're supposed to be specialising in dementia care. They should employ people who are committed and have an understanding of the job. There is no shortage of carers, but a shortage of committed carers."

"The money doesn't make a difference. It wouldn't matter if it [the care home] was some old building. If they can guarantee they'll follow the care plan, I'd be happy. But they don't."

"You can tell who is being looked after by the way they look. The priest always comments on how nice Mum looks. Other people don't have their hair brushed or they smell. You know that fresh urine doesn't smell. It only smells when it's been there a while and not been cleaned up. You can tell when people aren't being cared for."

Continuity of carers is very important to Pamela. Maria recognises one of her morning carers. "This morning they were signing 'My Old Man's a Dustbin Man'. However, Pamela complains that it is very difficult to get continuity. "I had to fight for it. You have to explain that it's good for the carer as they'll get to know the particular needs of the patient. It's good for the patient as they get to know how to care for them. Mum's face lights up when she sees them. It gives me confidence to go out."

"I'm not a racist but there were these two carers looking after one old man. They were either side of his bed talking in their own language over the top of him. He was there awake, but was just ignored." It isn't only a matter of language. Pamela says her mother has difficulty understanding different accents. "There was a French carer. She spoke good English, you and me could understand her fine. But Mum couldn't understand her accent. Mum kept saying 'What?' This carer assumed Mum was deaf."

"The Philippine staff in the care homes always seem to be good. They come from a culture of carers. But the new migration rules are keeping them out. One went home to see her family and they wouldn't let her back in."

Pamela has to explain her mother's condition to so many different sets of professionals and people that she has typed up and printed copies of Maria's detailed care plan, her medical history, her life history and the medication that she is on. Pamela keeps copies of these at home and in her mother's handbag. Every time she calls an ambulance or has to speak to a new carer, nurse or doctor she gives them a copy. She explains

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that you have to explain all of this information time and time again, usually in stressful situations, such as after her mother has had a fall. Having them available makes it faster and Pamela doesn't have to worry about forgetting anything. "Oh, you're organised they say. I wasn't always like this, but you learn quickly."

Although Pamela appears to be in control, her husband Simon is worried about how the stress of full time caring is impacting on Pamela's physical and mental health. Simon resigned from his job in part so that he could provide more support to Pamela. "It was partly because of the situation at home. I wouldn't have done it in any other circumstance ... I think one of the worst things is that there is no end date. If there was an end date you could make decisions better. You just don't know how long it could go on for." Pamela agrees that being the carer is taking a toll on her. "Carers die before the person being cared for." Caring for her mother has also sometimes led to family tensions, given the complexity of caring for Maria.

### Hospital admissions

Pamela says that Maria is increasingly frequently being admitted to hospital. This is usually after a fall and the family have to call an ambulance. "When the paramedics come, they are supposed to take Mum to Hospital X. But I have to insist that we go to Hospital Y. They have all Mum's notes. I don't want to go through everything with them. They can just tap into the computer and all the notes come up. Much easier."

Maria had been discharged from hospital the day before I visited. Then when back at home she had a fall. "Well more of a flop really, she just sits down. By Tuesday night she was short of breath, lethargic, more confused than usual and her mobility was much worse. We called the paramedics. Her blood pressure was up and she had a temperature. We went into A&E. It's always at night and so people are never around. She was in overnight. We got home about 4am, exhausted. Mum came out the next day, but she's always in a bad way when she comes out of hospital."

### Social life and interests

As Maria's health has deteriorated, the activities that she participates in have decreased. She enjoys watching quizzes on television as well as football, snooker and horse racing. She also enjoys playing bingo.

Maria was watching the horse racing on Channel 4 during our visit. "She likes the racing," explained Pamela. Maria leaned over to me and said, "I was fourteen, waitressing at [her parents cafe]. One of the city gents came in. 'You ever been to the races?' he said. He said 'Get your coat.' And off we went. He took me to the races." She told me the same story three times over the next 10 minutes.

Pamela says that she struggles to find things to talk about with her Mum. Maria's memory is so bad that she cannot recall what she has done that day. Pamela explains that her Mum cannot remember what she has eaten or has done at the day care centres. "She tells me that she has roast chicken and rhubarb crumble every day. She doesn't, but that's what she says. I can't have a conversation with her. I asked the day care centre to jot a few things down in a notebook: what she's had for lunch or what they did today. It'd help me talk to her. But they said they couldn't."

## Technology

Maria doesn't use any technology. She watches the television, but can't really concentrate on what is on and certainly can't use the remote control. Simon is highly computer literate, with experience in developing websites and writing content, and is in the process of starting up a freelance web-based business selling discounted utility packages. Pamela uses text messaging to contact the carers, using her 2G-style phone. Neither Pamela nor Simon have smartphones. There were no telecare or alarm systems in the house.

Providers have not always caught up with the benefits of the new technologies. "We didn't get back from the hospital until about 4 in the morning. Exhausted, we were. We didn't want the carers coming in the next morning, waking us up, as Mum wasn't here. I sent them a text. There was some confusion and the office then gets on to me the next morning saying I should have let them know and not to contact the carer directly. I shouldn't have their mobile number or anything." Pamela explained that she then lost her temper with the office staff, as it was 10am and they had been woken up.



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## 5.4 Winston and Mabel's story

Winston and Mabel, both in their 60s, live in extra care housing in South London. They moved there some time after Winston had a stroke. He is now paralysed on the right side of his body, which has severely impaired his movement and speech as well as his ability to do things for himself. He needs round the clock care. His wife cares for him full time and with support from carers at the extra care home.

### Background

Winston moved from the West Indies to the UK in the early 1950s. He lived in the Midlands at first and moved to London after a few years. Mabel also moved from the West Indies to London, where she and Winston met. They married in the early 1970s. They have lived in several places in South London. "We are proud South Londoners."

The couple have a large family, with more than ten grandchildren and they "can't quite remember how many great grandchildren". Their children all live in London. They come and visit every Sunday and they all go to church together. The family mostly visit them: "The children live in buildings without lifts and it is difficult for Winston." Sometimes the children come by to take Winston out for the day on his own, and "this gives me some time for myself," Mabel explains.

Before Winston had his stroke he worked for 35 years in a factory in Middlesex. Mabel worked on and off for a cleaning company. "We came here to work and we have worked hard all our lives. Family, faith and work, that's what's important to us."

### Winston's stroke

A few years ago Winston was on his way to work on the train when he fainted. He continued his journey and a couple of hours later he was working with heavy machinery when he had a stroke.

Mabel was working, cleaning council offices, when she got the call to tell her Winston had been taken ill and was on his way to hospital. "The shock was terrible. It came out of nowhere and was totally unexpected. One day he was fit and healthy, very active and the next day he had changed completely."

Winston also suffers from diabetes. Mabel says they put the stroke down to a combination of high blood pressure "that he didn't take care of properly" and the diabetes.

Mabel described the time after Winston's stroke as "hectic – it changed everything." Winston is visibly upset when talking about his stroke. He says it is a "blur. I can't really remember it happening". He says he felt "invaded" after having his stroke. It was such an intrusion always being "poked and prodded, going from doctor to doctor".

After a couple of weeks in one hospital Winston was transferred to another. He describes a period of intense occupational therapy and physiotherapy. Both Winston and his wife were very pleased with the care that he received. "The doctors and hospital staff did a lot of good work to improve Winston's condition and he has made huge progress since the beginning."

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But despite the improvements, Winston's mobility was still severely restricted and it slowly became clear that Winston couldn't go home. The building they were living in had a lot of stairs that would be impossible for Winston to negotiate. Mabel was still working: "I needed to work. I couldn't care for him and he couldn't live independently."

### Recovery period

Winston was assessed by social services and was placed in a nursing home: "I really hated it. I just stayed in my room on my own." Most of the people there had dementia, people didn't engage with each other, there was little activity and "the only thing people did was watch television". While Winston's speech is impaired he is very aware of what is going on around him, and despite speech difficulties he does his best to communicate.

Mabel says that she and the children could see that he was becoming more and more withdrawn the longer he stayed in the home. "He was completely isolated. It was frustrating for him to be there. He didn't feel it was the right place for him. He wanted to go home and be near his family."

His wife found this very difficult. "It was a very stressful time going backwards and forwards to the nursing home, working, responding to Winston's doctors and missing him because he wasn't there...I remember crying all the time. It was a worrying time for the whole family."

Despite the shock and confusion, they were extremely happy with the support that Winston received from the consultant who was an expert in strokes and who cared for Winston when he first went into hospital: "He was able to reassure us and answer our questions. He always explained what happening as much as they could."

Winston says: "If it wasn't for this consultant I don't know what we would have done." Mabel "just couldn't cope" at this time and was despairing about what to do. So after Winston was sent to the nursing home she contacted the consultant "in desperation" and asked him for help to get Winston moved. Mabel says she could see "him slipping away and I couldn't let that happen. I was going to fight for him".

The consultant then got in touch with social services and persuaded them that Winston should be moved into more appropriate accommodation. They are both full of praise for their social worker who eventually found them a place in the extra care housing.

"She really gave us time and attention. She explained things to us." Mabel and Winston had heard about extra care housing but had no idea how to get in. After they found a place in the extra care housing Mabel gave up work to care full time for Winston. "It wasn't a difficult decision. It was time. I was near to retiring and he needed me. We are here with each other now and we can ask for support when we need it."

### Extra care housing

Winston and Mabel's flat is spacious, bright and nicely decorated. It is cosy and homely with lots of personal effects: birthday cards, lots of family photos of children and grandchildren and prayers: "We have made it our own." The building is a mix of social housing flats and homes for sale. Winston and Mabel are social housing tenants.

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Their flat has two bedrooms, a kitchen, a dining and living area and a balcony. The bathroom is specially designed for wheelchair users, the doors are wide and there are bars all around the room and a hoist in the bath.

There are many special features in the flat that “make life a little bit easier.” There is an intercom so that they can see and hear visitors at the front door and let them in without going downstairs; the light switches, door handles and kitchen counters are low so that they can be reached by someone in wheelchair; there are several alarms with bright red string hanging from the ceiling around the flat which can be used to contact reception so that someone can come immediately if help is needed. Winston also wears a personal alarm around his neck: “We’ve used the alarms a few times, never for anything too serious. We haven’t had any major emergencies.”

The complex also contains a hairdresser’s, outdoor roof terraces, a green outdoor area on the ground floor, communal areas on every floor with comfy sofas and lots of plants and pictures and they both use these areas. The corridors are spacious with rounded corners and bars to hold. The lifts are big enough for wheelchairs. Even though Winston moves with difficulty and with the aid of walking sticks, these features mean that he can move between his flat and the communal areas on his own.

They have a television and watch it a lot, mainly the news and the gospel channel. They also watch a lot of movies on DVDs. They have never had a computer but Mabel in particular isn’t very enthusiastic about the prospect of getting one. She says it is too expensive – and they want to use their money for travel - and she doesn’t know how to use it so she would need classes. Their children and grandchildren are “always on the internet”.

There are also lots of activities taking place on the ground floor on a Wednesday. They have exercise classes, sing-alongs and painting classes, all run free of charge by volunteers from the Alzheimer’s society. Winston says that he “loves going to the singing and goes most Wednesdays”. There is also bingo that they both go to every so often.

They describe the extra care housing environment as “very supportive” and appear to have a positive attitude about living there. Their flat has every amenity they need for independent living but there is help there whenever they need it. They also like that it is “private and safe and if Winston becomes ill there is someone there to call an ambulance or to get the doctor.”

## Caring for Winston

Mabel now cares for Winston full-time. She is supported by carers who come every morning to bath and to dress Winston and they return in the evening to get Winston ready for bed. The pharmacy delivers the medication. While Winston and his wife can usually manage his medication themselves the carers sometimes help with this.

Winston needs assistance with day-to-day tasks like opening jars, cans or zips. He can’t prepare food for himself. Meals are provided in a communal area downstairs at a cost, but they usually eat in the flat and Winston’s wife usually prepares food. “She cooks great West Indian food.”

When they moved in, Winston was assessed to check what type and level of support he needed (for example some people need full-time carers). His wife does most of

the caring but finds lifting him physically difficult. So the carers come to help with this in the morning and evening – getting him in and out of bed, dressed and showered. They have a folder with Winston’s care plan with all relevant information including the names and contact details of relevant medical professionals, a description of Winston’s care, details of medication and important dates to remember.

Winston and Mabel have a good relationship with the carers. They say the carers are very respectful and friendly. “They talk to us and we have a nice conversations. They always ask us how we are and they seem genuinely interested.” Mabel says “it’s a two-way thing –we always remember to thank them for the hard work they do and let them know it is appreciated.” She says that they deal very well with Winston’s frustration with not being able to do things for himself. Their carers change from time to time and they have had carers of different nationalities (English, Filipino and African).

The couple talk a lot about Anna, the care co-ordinator at the extra-care housing, and they describe how she plays an important role in helping them negotiate the web of services they engage with: “We call her all the time to ask her any question. She will help us find something out. And we can trust her.” She is the first point of contact for a lot of things and the go-to person for general advice. (Not just for Winston and Mabel, it seems but for many other residents also.) And if she doesn’t have the answer she can put them in touch with someone who does. Anna recently helped them resolve a problem with social services when they were confused about their rental payments. “It’s not easy you know. Sometimes I just can’t get through all this paperwork. I miss things and it’s confusing.”

They have a bought a special electric chair and electric bed for Winston that he can adjust himself by pressing a button. Anna helped to look for the right one. These items were expensive and their children helped to buy them: “It was a stretch getting the chair. But it means getting up is a bit easier for him. It sounds small but it means a lot.”

“The children felt so happy and relieved when we moved into extra care housing.” Living in extra care housing means that Winston’s wife can take a break from caring. Last year her daughter took her on a break to Scotland. She said she felt safe in the knowledge that he would be well looked after while she was gone. But “I still worry a lot. I know he is stubborn and sometimes he just won’t ask for help because he doesn’t want to be a burden.”

## Travel and mobility

Winston and Mabel had just been to a concert on the Southbank on Saturday, Songs from Musicals. They were invited by their neighbour who lives downstairs and their daughter came as well. “There was a great sing-along. There was a lot of joy and fun.” Mabel says that it is important that Winston gets out and about, even though it can be difficult, otherwise “he would get so low”. Winston had a disability car but had to give it back as there was no one to drive it.

Going out and about around London and travelling is something that Winston misses doing since he had his stroke. Before he had his stroke they travelled abroad regularly, visiting family and friends in the West Indies and the USA and often going on weekend trips to all around Europe. Winston’s favourite city in Europe is Amsterdam. “I was shocked when I first went there and I saw the red light district and marijuana.” They

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both have a good laugh about this. He also loved that everyone cycled in Amsterdam. Just before Winston had a stroke Winston and his wife travelled to Eurodisney in Paris. There are pictures on the wall of this holiday and they remember this trip as great fun: “We felt like we were children again.”

When Winston first moved to London from the Midlands he loved exploring the city. It was unlike anywhere he had been before: “Everything was a surprise.” But now, getting around is difficult. Within extra care housing Winston can manage to move around with a walking aid but very slowly. “I feel safe. I know where I am going and it is not a busy place.” But moving around outside the home is another matter. To move around outside extra care housing Winston uses a wheelchair which someone – usually his wife – has to push.

Mabel was determined that Winston would keep travelling after the stroke. They have been to South Africa and New York since Winston fell ill – but travelling is becoming much more difficult now. Sometimes there are trips organised by the home and they went to Brighton a while back: “It was great to have someone else organise it.”

Winston would love a scooter. They both agree that this would give him a little bit more independence but they can’t afford one.

The ambulance comes to collect him for his appointments in the hospital. The GP is just across the road so Mabel can take him in the wheelchair. He has to go for regular eye appointments and uses public transport. This is extremely stressful for Mabel. It has to be a very well planned expedition and they have to give themselves plenty of time. Winston, on the other hand, loves going on the bus and wishes he could do it more often: “It’s a bit of fresh air.”

## Social life and friends

Winston goes to the exercise classes and sing-along sessions that take place in the communal area on the ground floor of their extra care housing home on Wednesdays. Winston has a good rapport with staff and other residents and there are lots of hugs and “hellos” when he arrives. He is very engaged with the singing and exercise: “I love to sing.” He starts chatting to other residents about the party they had for the royal wedding: “There was a lot of singing and music. But I couldn’t dance. I could only watch. I used to love dancing with Mabel.”

Winston has been going to the same church since he moved to London. He loves gospel music and loves hearing it every week when he goes to the packed church. Religion is a very important of their lives and they attend a local church. Mabel says that “prayer and faith helped me get through the dark days – sometimes I got so low when I didn’t know what to do. When I thought I had lost him”. Their faith and the support they get from members of the church have been hugely helpful to them and the wider family.

## Technology

Mabel has a mobile and receives several calls a day and she texts frequently. Winston had a mobile before his stroke that he used a lot. He got another mobile about a year ago but it fell into the toilet and it hasn’t been replaced. It is difficult for him to use it as he only has the use of one hand. He does use the landline.

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## 5.5 Sylvester's story

### Background

Sylvester is in his early 80s. He arrived in the UK from India in the early 1950s. Initially he stayed with his sister in the west of England; then he moved to London eventually he moved to South London a year later where he has lived ever since. "I felt at home straight away."

He has lived in sheltered accommodation for the last 20 years since he had a stroke. Sylvester says he is "very happy to be living here". His ground floor apartment is neat and tidy, and very spacious. There is a very pretty garden out front, with lots of colourful flowers.

Sylvester is Anglo Indian, originally from Mumbai. He says after the riots in India in 1950s and independence changed things for a lot of Anglo Indians. "We felt like outsiders and many moved to the UK." Being Anglo Indian is very much part of Sylvester's identity. "My schooling and education was British, our values and cultures are British so this is where we belong." He describes himself as an "active member of the Anglo Indian community," regularly attending events and festivals with family and friends. "I met a lot of people in South London. A lot of good friends."

### Community in South London

"I know this place so well, years of history. When I came here Churchill was in power and the local MP was Duncan Sands. I remember the name."

Sylvester says he has seen the place 'transformed.' A lot of churches have changed and are no longer used. "I used to be the only brown person but not any more."

"There is lots of violence. If people stop me in the street and ask for direction I don't stop. I just walk on by. You can't trust people. They carry knives."

### Family

Sylvester had many siblings in India and all of them, apart from one, moved to the UK. In the early 1970s he met and married but the marriage didn't last long and they divorced. Sylvester never remarried. "That's life I suppose. Things were difficult me for me after that."

His older sisters are all nurses and many of them have died. His 90-year-old sister lives in the Midlands as does another sister. He has a brother living in the North and he sees him from time to time. He keeps in regular telephone contact with his siblings in the UK.

He writes letters to his extended family in Europe, the US and India. He often writes letters by hand and his nephew will type them up and send them. "I like writing letters, keeping in touch. I love receiving them too."

Sylvester says his nieces and nephews keep him lively. "I don't know how many nieces and nephews I have. So many! They are all over the world."

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## Career

Sylvester trained as an engineer and worked in India. When he arrived in London he got a job in a factory; after nearly 20 years he was made redundant.

Shortly after being let go, he was offered a job in Wales but he didn't want to travel that far. "My family and friends, and everyone I knew was in London." So he decided to start an engineering course at the Engineering Institute Training Board. He later found a job for a large company where he worked for 20 years until he retired. "I get a good pension from there and I took out some shares in the company. That is where I made my money."

Sylvester enjoyed working. He had many friends and colleagues. He enjoyed the variety of tasks. "I was busy all the time." He worked in invoicing and felt very much valued at his last employer. "I saved them thousands and they were satisfied with me."

He says didn't want to retire. He wanted "to work on... but they told me I was 65 and I had to go." He has good memories of his retirement party: "They gave me a good send off – it went on all night."

There is a club for the retired workers of this company and they have get-togethers at different locations that Sylvester sometimes attends. His big plan post retirement was to travel the world and despite his stroke he has managed to travel a lot. His other plan was to spend more time with family and friends and he feels he has achieved this. "I haven't done badly."

## Stroke

A month after Sylvester retired he had a stroke. It is clear that the experience took its toll on him: "I felt robbed of everything. I had so much to look forward to and it was like it was taken all away from me."

At the time of his stroke, Sylvester was living alone in rented accommodation in South London. "It was a cosy one bed apartment." His cousin had been visiting from abroad and they had met one evening for "a bite to eat and sip of rum. When I got home I was dizzy and I went to bed. I could sense there was something wrong. I woke up vomiting at 2am and I vomited from 2am until 6am non-stop. Then I called my niece. She came and called the ambulance. And I was taken to the hospital."

At the hospital Sylvester had to wait on a bed in the corridor. "I don't remember for how long. My family told me this. They were upset." He spent two weeks in hospital. "It was a dreadful time but the doctors and nurses made it a bit better. They were very very good."

"When you have had a stroke nothing is the same as before. I didn't want to be dependent on anyone. I had always done everything for myself." Sylvester was very weak after his stroke and his mobility was restricted. He was not paralysed and he did not lose his speech. "I was still able to communicate, thankfully, but I had to take a lot of medication - so much."

Sylvester later had another stroke but he didn't notice it happening until after he went to the doctor.

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## Recovery period

When he was discharged from hospital he went back to his own flat. His sisters came to stay with him at different times. This was helpful as they were both senior nurses. “They knew what was what. They knew about the medication and how to deal with people. I just wasn’t ready for any of it, physically or mentally.” His niece also came to care for him. This was difficult for Sylvester to accept at first: “I don’t want to give anyone any problem. They have their own lives and their own problems. I don’t want to be a burden.”

At the same time he accepts that their help and support was necessary: “I couldn’t do it on my own. I needed support. I was a different person. It took time to get my bearings and know myself again.”

After the stroke his movement was severely restricted and it was clear he had to move flat; he wasn’t able to use the stairs in his own apartment. “It set me back. It did set my back.” He can’t remember the exact details of this process. He was in touch with social services at his council. They offered him a few places. “To be honest, they weren’t satisfactory. I wanted like-for-like. I wanted a quality of life. They offered me a bedsit. I didn’t want to live in one room and stare at the television. I didn’t want to be defeated by this thing.” Eventually he was offered a place in sheltered accommodation.

## Sheltered accommodation

Sylvester’s flat is on the ground floor and he speaks very positively of his experience there. “I like it, of course I do. I am still here after 20 years and I am near lots of old friends.” Sylvester had been burgled in a previous apartment, just before his stroke and this left him feeling anxious and insecure. However he feels safe in the sheltered accommodation: “I don’t ever feel alone. When I was robbed I couldn’t sleep. Here it’s different.”

“I am friends with a lot of the shopkeepers on the street and I used to always pop in for a chat. They all know me still.” The newsagent nearby brings the paper every day; if he needs milk he can call them and they will drop it around; the pharmacy delivers medication.

His niece and nephew live nearby and they have the keys for the flat so that they can drop in whenever. “They give very good support.” They visit him at least once a week. They arrange his shopping, help with cleaning and make sure his hospital appointments and medication are in order.

His niece “manages” his diary. There is a big calendar hanging on the wall with details of every appointment and upcoming event that Sylvester needs to be aware of: shopping deliveries, hospital appointments, birthdays, visits from family members, outings. His niece prepares food and brings it to him sometimes. His niece and nephew also look after his banking.

There are alarms in every room in the apartment that are operated by pulling a string hanging from the ceiling. Sylvester also has an alarm around his wrist. If there is anything wrong he can use these alarms and someone will come. “Luckily I haven’t had to use the alarms yet.” From Monday to Friday it is the warden in the sheltered

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accommodation who responds, after that there is a central control centre in the local council that responds.

There is a communal phone allowing Sylvester to dial his neighbours quickly and freely. There are about 30 people living in the sheltered accommodation. "I keep myself to myself but I have a few good friends. I have my privacy and independence." One of his neighbours "is losing it and she forgets to eat. I give her a call to remind her. I say hello and have a chit-chat but there are only a couple that I call friends. Terry across the way is my good friend. We go back. There is Noreen living upstairs and Sean a few doors down".

According to Sylvester everyone at the sheltered accommodation has "mobility issues" and some people are getting forgetful which can make mixing difficult.

Sylvester has a good relationship with Jenny, the warden at the sheltered accommodation and she pops in once a day. "She is very helpful. I chat with her now and then. It is good to know she is around." Jenny sends written updates to all the tenants giving information about events taking place, birthday celebrations and Sylvester likes being kept up-to-date like this.

There is a community hall in the sheltered accommodation. It is for everyone that lives nearby and older people from some of the other homes in the area also come to visit. Various meetings take place there.

The local MP has come to visit the community hall and Sylvester went to the meeting. He went to complain about the council as he feels they are not maintaining the sheltered accommodation as they should, especially the common areas, gardens, paths etc. Sylvester has also written to the head of the council. "It's distressing that the place is not being kept. They say they have no money. This whole country has gone to the dogs. These politicians are all talk no action. I pay enough to stay here."

Sylvester has a little garden in front and behind the house but he can't do the gardening anymore. He still tries but he needs someone to come and do the gardening. The one thing Sylvester would like is a new bathroom. "I need a new arrangement." He would like the bath adjusted. At the moment he has a hoist and has to manage getting himself in and out of the bath. But he worries that he might get stuck. But all in all Sylvester says he is "very happy to live here and I want to stay".

## Health

Sylvester has had regular hospital appointments and check-ups since his stroke. Jenny the warden at the sheltered accommodation arranges transportation for the hospital. "I have to be transported in a wheelchair as my legs have given up." He is mostly happy with treatment in the hospital apart from one time he was left waiting for four hours to be seen for an appointment.

Sylvester suffers from bad arthritis. "My knees are very bad and my hands are not so good. There is no cure for me, for my arthritis. I am housebound." Sometimes he is in terrible pain and uses a lot of gels to ease the pain. He has acupuncture and he finds it helpful. But he doesn't like taking painkillers. The doctors have suggested a knee operation but he "doesn't know what is the point".

His hearing in his left ear is very bad and he is diabetic. He doesn't take any medication for his diabetes – he just manages his diet. He can't eat fruit, only blackberries. His kidneys also give him trouble. He has to take a tablet for his kidneys every day. He regularly goes to a chiropodist (who comes to the community hall in the sheltered accommodation) and he has to travel to get his eyes checked (due to his diabetes).

"I look after myself." Every day Sylvester takes a variety of medication including aspirin, paracetamol, kidney tablets, pills for his bowels, salts to relax his joints, blood pressure tablets and calcium tablets

## Services

Sylvester describes the community matron, Mandy, as "absolutely fantastic. I can rely on her. We have a great relationship. I can pick up the phone any time. She visits comes once a month and she sees to everything. She is very helpful."

Sylvester has problems providing blood samples. He finds it very difficult and Mandy is very understanding about this. "She helps with communicating with the foot clinic and the blood clinic." Mandy has suggested applying for a carers allowance but Sylvester says he "is having none of it. I don't want a carer. I don't want to be a scrounger. I can't be bothered with carers."

The GP's surgery is nearby. "It's just around the corner. It's great that it is so close. I can call them and they come to visit me. They always try to understand me."

He recently saw a leaflet in the surgery about paying for your own funeral and this prompted him to pay for his own funeral through Age UK. "I don't want to be dependent. If anything happens my family gets everything. I have made my will and planned everything."

Jenny (sheltered accommodation warden) and Mandy (the community matron) give Sylvester most of his information about services available. "I just pick up the phone to ask them any questions. They will always give me an answer, and if they don't know the answer they will go and find one and then get back to me."

## Mobility

Sylvester moves very slowly with two walking sticks. He sometimes uses a walking frame in the house and it takes quite a long time to walk from his apartment to the community centre, about 30 meters away. He also has a wheelchair but someone needs to push him and this can be difficult, "I am a heavy load."

If he does get out it is because his niece and nephew take him out. "Other older people around give me inspiration. When I see them walking around."

When talking of his mobility problems he says: "I have got to live with it. I've got to respect ageing." He clearly misses getting out. "I hardly go out now, never really on my own. I nearly get run over." Someone suggested getting a scooter. But Sylvester says: "I don't want one. They are all getting stolen." He never uses public transport.

He used to always enjoy going to nearby shops. "I used to like to take a little walk. They all know me. I have been around a while." Sometimes Sylvester will still take a

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walk to the barber down the road to say hello. "I tell them stories from this area that they are too young to know."

Sylvester travelled a lot and continued to do so after his stroke right up until last year. He used to visit India when his parents were alive, but less so now. He has been on several cruises. He did a world cruise for three months and it was fantastic. "I have been on all the ships all over the world." The last cruise he went on was last year. He would like to go on another one but he says he is not sure if he is able to do it anymore: "I don't know. I just don't know." He has gone on several cruises on his own, but in the last few years he has been accompanied by one of his extended family members. "I need someone to take care of me now."

### Social life and hobbies

Sylvester has a passion for history and current affairs. He loved to study history at school and is still an avid reader of the subject even though his eyesight is now failing and sometimes he has to use a magnifying glass. He talks enthusiastically about his love of history: "Every day you are learning. I am still learning." Sylvester loves to talk politics and to keep up with current affairs. He had just seen a report on the famine in Somalia and told me how upsetting it was to watch.

Religion was always important to his family in India. Sylvester prays every day and he reads the bible. He used to go to church once a week. "My faith always gave me strength. It was something to cling to when I first arrived. Everything was new but that was familiar." There is a church right beside his flat that he used to attend every week but since movement has become more difficult for him he no longer attends. "I felt part of the community, part of something bigger. Now I feel like something is missing, but what to do? The spirit is willing but the flesh is weak."

### Technology

Sylvester likes to watch Newsnight and Question Time on TV, "I like to keep up with current affairs."

He doesn't use the internet and he doesn't own a computer. "My nephew says it would be too much. I need to keep things simple. It's not for me." But he is aware of the power of computers and he says that sometimes he gets his nephews "to Google things" and to look things up on the internet for him.

His nieces and nephews all have mobiles. But Sylvester has never had a mobile and prefers his landline. He calls the USA, Canada, India and Europe. "I need it. I use it to keep in touch with the world. I would be lost without it. I call the GP and the pharmacy."

### The future

Sylvester is taking every day as it comes. "You say to yourself you just don't want to do any harm to your body. You take of yourself. Keep company with friends and family."

He says that if possible he would like to go on another cruise. "I got the brochure. But someone needs to come with me. I don't want to be a burden."

Sylvester is fatalistic about his future and talks openly about death. "At this stage there is nothing really I want. You are just waiting to go. To me this is the end of the road."

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## 5.6 William's story

William is 87 years old and has been a farmer in the South West of England all his life. "My family have been farming here as far back as you can go." He moved around the countryside on different farms as a child before eventually settling with his family in the Exmoor area.

### Family

William's wife Monica died about two months ago in her late 80s. The couple had been together for nearly 70 years. William started talking about her immediately at the beginning of the visit, and he was clearly still grieving for the loss of his wife.

Monica had Parkinson's disease and William cared for her for nearly three years. She was suffering from dementia but William says, "I know she knew me".

William had become used to doing everything for Monica. His daily routines revolved around her. "I did everything for her in the end. She couldn't do anything. In the morning I used to wash her and dress her and put her in the chair. She always had her porridge in the morning – summer and winter. I haven't had porridge since she died. In the end Monica couldn't eat solids. I was putting everything in the blender for her."

William and his wife have lived in the South West all their lives. Monica always worked with children: "She was very good with the children and grandchildren. She worked in private schools and then she worked as a nanny for a few families." It was hard for the children and grandchildren to watch Monica become more ill. "My sons couldn't bear to see Monica like that." For William it was heart-breaking to watch her get worse. "I could see her going downhill. She was so muddled. I would wet her lips and give her a kiss. I am sure she knew me."

William says that he relies on his family first and foremost especially his elder son and daughter in law who have been a huge help since Monica died. William has three sons who all live within five or six miles. "They are around all the time." Every day at least one of his children calls in to see him. One son is an agricultural professional and "pops in on his travels all the time". "They are tremendous. We are always on the phone." He uses his landline a lot to stay in touch with his family.

He has a mobile phone but he doesn't use it much. He used to take it when he was going out to call Monica when she was alive. He doesn't use text messaging. "I never learned to and it is too difficult to see."

William has several grandchildren and great grandchildren. Many of them live close by and he sees them frequently. His eldest son took over the family farm when William retired. His grandsons work on the farm. William says that his great-grandson wants to be a farmer too. He is very happy about this: "It's keeping the tradition in the family." He describes his great grandson as a "great little farmer".

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## Caring for Monica

William cared for Monica for several years before she died. “I did everything for her in the end: the cooking and cleaning. She couldn’t eat on her own. I had to feed her.”

William also received support from carers to look after his wife. “They came in the morning, at lunchtime and in the evening. They were all ages. Young and old. They spent time with us. I couldn’t fault them. We always had the same bunch.” The carers helped wash Monica every day and lift her in and out of bed. If they were having trouble somewhere else they would always call and say they would be delayed and William found this reliable and reassuring. Having the support from carers meant that William could go and play bowls. Sometimes the carers would bring his wife to watch. The carers were given time to take study-leave and develop their careers and William and his family were pleased to know that their carers were qualified.

William was extremely happy with the quality of care that Monica received. “They talked to her very kindly even though they were in difficult situations. They had terrific respect. They maintained her dignity.”

William takes solace knowing that Monica had a good relationship with her carers: “Monica loved them. They would even have fun with Monica and some banter and they brought some laughter.”

William and his family are also comforted by how the carers dealt with Monica when she was very ill towards the end of her life: “How they handled her and how they spoke to her right to the end. It was very touching.”

As well as caring for Monica the carers made an effort to get to know the family and also helped William. “They sat with me on the downs. I miss them awfully now that they aren’t here.”

“You won’t find a better community health service,” according to William. All the professionals he deals with as “top class people”. Most of them are from the town. “Most of them I know them, or their fathers or their grandfathers. So there was always something to talk about.” When Monica died William wanted to show his gratitude to the carers and give them some money but they couldn’t accept it. So he gave them Marks and Spencer’s vouchers. William feels like he “couldn’t be in an area with better for caring.”

The community matron is “tremendous” and “fantastic.” She still calls to say hello to William. She was the one who told them they could apply for help to pay for the carers. They had previously been paying for the carers. “But that help all stopped when Monica died.”

## Monica’s death

William remembers vividly the evening that Monica died. They ate supper together. “Do you want strawberries and cream?” William had asked. “Oh yes please,” Monica responded. “That was the last thing she said.” Monica died in the middle of the night. “I was tired and went to sleep beside her. I woke up at 12.30am. She was breathing. I woke up at 1.30am and she was gone. I had my arms around her.” William called his son who is a farmer. He and his wife came straight away. When his son arrived they called the doctor on call. “He wasn’t English, that doesn’t bother me. But the only

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thing he said was ‘gloves please.’” William couldn’t remember at that moment where the gloves were. William felt that the doctor should have come equipped but he didn’t even pass on his condolences and left a very negative impression. “He had just come into a house where someone had died and the family was in shock. I had just watched my wife die. I didn’t like that attitude. It was disrespectful, I didn’t feel good about it. I hate complaining but I told the community matron.”

### Grieving for Monica

William is still coming terms with his wife’s death. The living room is full of pictures of Monica, the children and grandchildren. “I talk to the photos and I tell her all the things I couldn’t tell her when she was here.” William’s family is aware of what he is going through. “I talk to them every day about it. If I don’t see them I ring them to talk to them.” The neighbours have been a source of great support and comfort since Monica died. Several of them call into house on a regular basis and William said he “can’t count the number of cards and phone calls I’ve received”.

He has tried different things to help him feel better. He was visited a bereavement counsellor. “I suppose it was helpful but right then I didn’t see the point of it. There are plenty of people around trying to talk to me. After they left the feeling was still there.” He has also been prescribed some medication by the doctor but he is reluctant to take it. “I have got a big bag of antidepressants but I am not taking any of them. They have side effects; you have to get off them.”

Along with family, the community matron has been great support for William since Monica’s death, “I can just talk to her and she listens.” The family got lots of messages from the people all over the area: “Even the girls in the fruit and veg shop sent a lovely card.” Despite this William still feels very down. “Things come in my mind that shouldn’t and I have a bad day. I feel down and I feel all alone with my worries.”

### Health

William has his own health problems too. He has had an aneurysm and prostate cancer and he has had several heart operations. William has a history of heart problems. He had open heart surgery in the 1980s in a London hospital. Since then he has had “two or three little heart attacks.”

The last time William was in hospital after a heart attack he was in intensive care and thought he would die. He was in hospital for two weeks. He was then transferred to the community hospital nearby to recuperate. When William was in hospital, Monica went into a nursing home nearby. She stayed there for a couple of weeks after William was discharged to give him time to recover properly. He visited nearly every day in the nursing homes and was reunited with a 93 year old cousin that he had lost touch with. The pair remained close since and William still visits him on a regular basis.

He remembers his first heart attack very clearly. He had gone to the East of England for two weeks to work on a friend’s farm. He felt very tired one evening and had “felt a slam” his chest and a “fantastic pain.” The next day he tried to work and continued to work for 10 days but he wasn’t feeling right. Eventually, when he returned home, he went to the doctor who told him he had had a heart attack and survived it. “Then it all started. Going to the doctor all the time.” After that William was sent to the London hospital to have his heart bypass. “I never smoked another cigarette again after this.”

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The most important people that help William manage his health are the local GP and the Community Matron. “You couldn’t get better than my doctor and the community hospital is great.” William prefers being at the community hospital to the nearest district general hospital. “They have more time to see you and nicer food. In the other hospital (the local District General Hospital) they don’t have time to see you.”

William says that his first heart attack “knocked the stuffing out of me.” He had found it hard coming home after his first heart attack. “I needed a lot of time to recuperate and Monica took great care of me.” He continued to farm after his first heart attack. But when he reached 70 he gave up milking in the early mornings. “I needed a rest.”

### Home and community

When William retired he and Monica moved from their farmhouse to a bungalow on the farm. His son and daughter-in-law moved in to the farmhouse. William says they were very happy to move and hand the running of the farm over their son. They put time into finding a place to live that would be right for them and their needs: “I have seen to many farmers holding on to the reins for too long. I made up my mind never to do that. I let [my son] in on the business early so he could learn and he could see how things are done.”

Shortly after that, William and Monica moved into a house closer to the town centre, where they lived happily for the last 11 years. “When we moved here Monica could walk up and down the town.” The house is a very well kept bungalow on the ground floor with easy access with two bedrooms, kitchen, bathroom, living room and dining area. There is a small garden where William used to grow vegetables but when he started caring for Monica, he had to stop. “I loved doing a bit of gardening. It kept me active.” Specialist equipment was installed for Monica so that it was easier to bathe and wash her.

William says he is very happy living there. I know everyone living nearby. “It is a very safe area. We have never had any trouble. Neighbours often pop in. I feel lucky. If I was in a city it wouldn’t be like this.”

He has played bowls all his life and has been a member of the local bowling club for the last two decades. He has several medals and trophies from tournaments. He used to travel all over county playing and Monica loved to come along. “All the ladies would make the tea and sandwiches. There’d be a lovely spread.” Even when she got sick the carers would take Monica to come and watch William play. But since Monica died William has not been able to play. His friends from the club have given him “great support”. They call into the house and phoning encouraging him to return. But he doesn’t feel quite up to it. “I have lost all interest. I haven’t had the energy to go back to bowls. I am only interested in talking to the photos.”

William and Monica were active members of their local church community in the town. “The Church was completely full for her funeral.” The collection at Monica’s funeral went to the Parkinson’s society: “After what I saw Monica go through, I want to do anything that can help.”

Monica and William went to the service every Sunday. William enjoyed Sunday mornings at the church with Monica. He would be at the door welcoming people and doing the collection. But William has found it hard to return to the Church since

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his wife's death. Since Monica died the minister from the Church has visited William several times: "He looks in on me. He's been marvellous."

William watches quite a bit of TV for company now, mainly current affairs and antiques programmes. He records a lot of programmes and uses the playback digital playback facility.

William has a lot of CDs and likes listening to classical music especially Beethoven and Radio 3. Many of the CDs are presents from children and grandchildren.

He misses doing things with Monica. His sister-in-law (and neighbour) goes to the coffee morning in the town. She has been encouraging him to join. They meet once a week in town for a coffee or lunch. Every so often they go on a coach trip. William doesn't feel very enthusiastic about it at the moment, "It's hard doing things without Monica."

## Mobility

William still drives. His car is parked outside the house. He used to drive Monica and take her out in it, "except at the end. It was too difficult for her". Towards the end she used a wheelchair and William used to take her into town in her wheelchair on a nice day.

Since Monica died he has been going for long drives in the countryside. A couple of weeks ago he went for a drive one day but got very upset thinking about his wife. He knows his children and grandchildren are very worried for him since Monica died.

William continues to cycle around the town "to nip down for the paper and load the basket up with some shopping." In June he crashed his bicycle. The basket was so full that he found it difficult to steer and he fell off. People came to his assistance quickly. He wasn't badly injured. He went for an x-ray and was told that he had a crack in his spine, but that it wasn't new. He also has some problems with his balance and his family have asked him to stop cycling as much or at least to wear a helmet. They are also suggesting that he should wear an alarm around his neck. "They wouldn't tell me to stop completely. They'd never tell Pop what to do."

## Daily life

Daily life without Monica has been an adjustment that William is struggling to get used to. "Every day revolved around her. Every thought I had was around her. I did everything for her in the end."

William cooked every day for Monica and since she died he has only cooked lunch once. All in all, William feels that he has everything he really needs. "I have a good family at the end of the phone, but I just can't help missing her. A good day is when all the things running through my mind recede in the distance... when the happy memories come back."

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## 5.7 Alfred and Margaret's story

### Background

Alfred and Margaret (both in their early 80s) live in a large and comfortable bungalow in a small village on the edge of Exmoor. Margaret suffers from a rare condition that affects the nose, lungs, kidneys and other organs. She is housebound: "I haven't been past the front door for 12 months and one week", she explained to me from her armchair. Alfred is reasonably healthy and leads an active life. He is able to drive and provides the majority of Margaret's care.

Alfred and Margaret are both from a farming background. Alfred was born in the county and grew up locally. Margaret was originally from the neighbouring county. In their younger days both were active members of the Young Farmers Club. They met at a dance and married in 1955. They ran a beef and sheep farm that had been in Alfred's family for hundreds of years. They retired nearly 20 years ago, passing the farm onto their son who now runs the family business. They moved off the farm and bought their current house, in the locality.

Although retired, Alfred continues to play an active role on the farm – "helping with odd jobs". Margaret teases Alfred that most of his jobs involve "standing about in the middle of the road". Alfred rather defensively explains that someone has to stand in the road to stop the traffic when the cattle move from one area to another.

As well as the son who inherited the family farm, Alfred and Margaret have a daughter who married a farmer and lives locally and a number of grandchildren.

### Daily lives

Their daily lives have become remarkably similar since Margaret became housebound a year ago. Margaret laughs as she described it: "It's the same every day; nothing changes. I can give you it hour by hour if you want!" She went on to describe her usual routine: "Alfred brings me a cup of tea at about quarter to seven and then breakfast of toast and marmalade at about quarter to eight. The carers come and give me a wash between nine and ten and then I'll listen to the radio in bed and have a sleep. Alfred helps me out of bed at lunchtime. We'll read the papers and the post and a neighbour might drop in. Then we'll watch sport on the TV in the afternoon. Sometimes an ice-cream van comes around at about five o'clock. We'll watch some more telly, eat and have a drink or two. Then it's time for bed again."

Alfred's day revolves around caring for Margaret. He does all the shopping and cooking, "Some mornings I'll cook something hot, but if we have something cold, I'll get to the farm for a couple of hours. There's always something that I can do to help out."

Alfred is keen to emphasise that that they manage well during the winters. "When we bought the house we made sure the walls and roof were insulated. All the windows are double-glazed. That wood burner gives out a hell of heat. It's like an oven in here." Alfred cuts his own logs, using a chainsaw, from the wood on the farm. "That reminds me, I must get up there and get on with it. We tidied up some of the hedges and I

should get up there with the saw." Alfred has a four wheel drive and therefore has no problems getting around in the snow or bad weather in the winter.

## Health

In the mid 90s, Margaret started experiencing intense pain in various parts of her body. "I'd wake up in terrible pain. It might start in my shoulder but then it would move to my leg. Nobody knew what it was. It'd move about. I went to the hospital, but they didn't know what it was. I then had to go to the (larger county) hospital.

They brought doctors from all over, even from London. They had me on steroids for a long time." Margaret explained that the doctors finally concluded that she had a rare disease, and told us the long, complex name of the condition. "I bet you haven't heard of that then? It's a disease of the blood and immune system." She pulls out a sheet of paper. "Look, so many people don't know what it is that we've got these little slips to explain it to new doctors and nurses who might come." The condition she has is life-threatening due to the organ damage it can cause. Margaret requires long-term deliberate immune-suppression.

Margaret also has problems with her blood pressure and water retention, has a heart condition and has a catheter fitted. The district nurse visits once a week and administers an injection. Once a month Margaret has what she describes as her "big day" when the nurse takes a blood specimen and changes Margaret's catheter.

Although Alfred is fit and active he suffers from high blood pressure and is diabetic. He had to have a knee replacement several years ago. His left leg is now giving him some pain and the doctor had to drain some fluid off it. "It's okay if I'm driving as I can keep it straight when I get into the car, the problem is when I'm a passenger and have to bend it to get in. I'll probably have to have the other knee replaced soon."

They are happy with the health services they have experienced, particularly their GP and their community hospital. "The only problem with the hospital was the patient next to me, she never shut up!" laughed Margaret.

## Care eco-system

Margaret and Alfred's two children live nearby. They come around regularly, but as Margaret is quick to point out, "They're busy. They've their own lives, their own families and businesses to run."

A carer from social services visits Margaret every morning to give her a wash. Margaret is full of praises for the carers. "They're very good, they do what I ask them and they're very sweet. I'm getting to know some of them quite well nowadays." Margaret explains that the carers vary and come from all over the county. "One time the agency was sending them from as far away as the next county. Miles away, it is." Margaret doesn't mind the variation of caring staff, but wants to know who to expect. "They send me a programme every Saturday, I like to know who's coming," she says, unfolding a letter which has a list of names for the week ahead. "You see I know this one quite well. She's a lovely girl; looks so young. I couldn't believe it when she told me she had a 15 year old son."

Margaret and Alfred have supportive neighbours. "The lady across the road helps keep the house clean and all the neighbours are very helpful. You can always call on them

if you need something.” The neighbours in the opposite house buy them the local paper from the village shop and post it through the letterbox each morning. While the community provide support, Margaret and Alfred have no interactions with the formal voluntary sector.

They are very happy with the care and support services they receive, describing them as “excellent”.

Both Margaret and Alfred are good-humoured and have a positive outlook on life. Despite her mobility problems and poor health, she is full of jokes and reflects stoically on her condition: “There are a lot of people worse off than me.” However, it is clear how their lives are dependent on Alfred’s mobility. He drives and therefore can do all the shopping and provide for Margaret. They would be extremely vulnerable if Alfred was to become more fragile or was unable to drive.



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## Social life and interests

Alfred and Margaret have Sky TV and spend much of their days watching sport. There was a Test Match in progress on the day I visited and the couple were glued to the cricket for much of the day, discussing who had played for whom and which of the cricketers' relatives they knew who lived in the local counties. Both Alfred and Margaret had been umpires for village cricket games when they were younger. In addition to cricket, they enjoy watching tennis and football (supporting Tottenham Hotspurs because they like Harry Redknapp). They also like watching horse-racing, and used to go to the races regularly.

Margaret's illness has had a dramatic effect on their social lives. Friends visit regularly, but Margaret acknowledges that this is not the same. "We used to go to the pub for Sunday lunch and go for drives, you know around the place and going to see people, but not anymore. We tend to drink at home – you should see our drinks cabinet." Margaret stopped smoking a couple of years ago having smoked over 20 a day for more than 20 years. "I still fancy one, but he won't get them for me. Can't do much about it anymore," she jokes.

Margaret used to play skittles in the local pubs and had been on a local political party committee. When she was younger she was an active member of the Young Farmers. Alfred used to enjoy riding and fox hunting.

## Technology

Both Margaret and Alfred are able to work the television and satellite remote controls. They have a VHS video player, but lament that they are unable to tape programmes from the TV following the switch from analogue to digital television. They have analogue radios in the house and two telephones. Alfred has a mobile phone that he uses only for calls. "I wouldn't know how to do anything else with it." They don't have a computer. Margaret says: "My grand-daughter looked around the house and said 'Granny, what you need is a computer.' A computer? I wouldn't know what to do with it. The people across the road do that online shopping. I don't understand any of that. No, we like things simple. All this technology and change is scary."

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## 5.8 Doris and George's story

### Background

Doris and George both in their early 90s live in a two-storey cottage at the top of a gravel lane in a village on the edge of Exmoor. George has had a stroke and a heart attack in the past three years and his mobility is limited. He can no longer get upstairs and sleeps on a makeshift bed in the living room. George had had a fall the day before our visit and spent his time in an armchair – much of it on oxygen. Doris is physically fit.

George is quiet and spent much of our visit dozing in and out of sleep. When awake, he struggled to hear the conversation. Doris, on the other hand is full of energy and does most of the talking. She explained that they have been married for 70 years and jokes: "That's the equivalent of three life sentences for murder." They have lived in the cottage since the early 1960s.

George and Doris have three children. One grown-up child lives with them but is not involved in their care; their two sons live in the nearest main town and visit regularly. One of them, Phillip, is visiting the day I interviewed George and Doris.

The couple are not well off and get by on state pensions and a small carer allowance. George had been a labourer on local farms and in a nearby quarry and Doris had been the caretaker in the village primary school. Both had been forced to stop work in their early 70s after being involved in a serious car accident. Both George and Doris had been badly injured, with Doris spending seven months in intensive care. They look back on this as a major turning point in their lives, in terms of stopping work and the start of different health problems.

### Health

Doris explains that three years ago George had to go into hospital after he had had a heart attack and a stroke. George had been ill for some time but "didn't want to make a fuss." Phillip, the son, explained that one day he visited the house and "Dad looked worse than death when I got there. I drove him straight to the hospital. People had to get him out of the car. He couldn't walk. They said he'd had a stroke."

George and Doris are happy with the quality of the medical care they receive, "I can't grumble about our doctors," said Doris. "Whenever I call they tell me that one of them will call back. They always do at the time they said they would." However, it is noticeable how both Doris and George talk about not wanting to "make a fuss" or "be a bother". Although Doris focuses all her attention on George and his health needs, she is also in her nineties. Phillip, their son, worries that his mother doesn't look after herself. "She's had stomach pains for weeks now, but won't go and see anyone about it. She concentrates on my Dad. When the doctors or nurses come, they come to check Dad. But I worry about Mum too. If she gets sick, it's not just her but Dad as well. Who'll look after them?"

Doris and George get confused about the sequence of George's health conditions and what exactly is wrong with him, and have little understanding of the medication he is on. They showed me one of the packets of tablets he takes – Warfarin following

his stroke. Doris, explains that a district nurse visits them fortnightly and takes blood samples, after that they get a letter telling them about a new dosage. Although Doris is not entirely sure what medication George is on, she is able to administer it. “When it snowed last winter the carers couldn’t make it up here. His pills are in this box,” she says, showing us the yellow daily pill box. “So I know what to give him for a few days. He’s got his inhalers and we have the oxygen machine. If the power goes, there’s a big cylinder out the back.” Later in the morning the oxygen machine starts beeping. “That’s the filter,” Doris says confidently. “It’s a little gauze thing. They showed me how to take it out and clean it. Fills up with dust you see.” Doris was shown how to use the oxygen machine and is very proud of her ability to use and service it.

George was last in hospital about three months earlier. “He was in for three or four days. His chest you see,” Doris explained. When George went into hospital he was using a walking frame. When he was discharged they kept the frame and gave him a stick. Nobody had explained this change to Doris or George. “They kept his frame and gave him this stick. Not sure what for, but it’s no good see. If he falls, he’s got nothing to keep him up.” Doris demonstrates, showing me how the stick can fall from under her. “With the frame he could get about. Now he can’t. I don’t know why they gave him this stick. It’s not surprising he fell over yesterday.” After George’s fall the previous day, Doris got an older frame out of the shed.

### Care eco-system

Doris is George’s main carer. Two of their children regularly visit and tend to the large garden, which is brimming with produce. George had been a keen gardener and the two sons keep the family tradition going.

George’s mobility is poor. He is unable to go upstairs and as the house doesn’t have a bathroom downstairs, he has to be washed from a bucket and uses a commode. They would like to have a stair lift fitted so he could get upstairs. Phillip would also like to see a shower unit fitted to his parents’ house. “It’s not hygienic only having a scrub wash. He can’t get upstairs so he doesn’t get washed. They said they’d fit a stair lift. That was years ago. We are still waiting.”

Carers from social services visit George twice a day – morning and evening – to wash him and to put him to bed. George goes to a local authority funded day care centre in the local market town once a week which he enjoys. “They come up the lane and pick him up,” Doris explains. “It’s the only time I have a break, but I still worry he’s going to have a fall or something.” They pay £24 pounds a month for the day centre: “Not bad, as they give him a good meal.” George tells me he particularly enjoys the quizzes, bingo and sing-alongs. The family is discussing sending George to the centre for another day every week to give Doris a bit more of a break. George seems to like the idea and Doris is keen to have a Friday off, as she can catch the bus up to the nearby large town to “do a bit of shopping”.

We asked Doris and George how they had found out about the day centre. “The doctor I suppose,” thought Doris. “But that’s the problem. It’s all so confusing. I don’t know what we’re entitled to, or who to ask. Somebody told me I could have free false teeth or new glasses, but I don’t know. Who do you ask? I don’t know if we can get more. It’s all so confusing.”

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I asked Doris about what it is like for her being a carer in her 90s. “I get depressed. It’s hard doing it 24 hours a day.” She sighs. “But I’ve got no choice. I live day to day. I don’t want to be a burden.”

Throughout the day it becomes clear that various members of the local community also keep an eye on Doris and George, dropping in with groceries or just for a conversation. Doris talks a lot about how the village has changed and most of the people she used to know have died or moved on. “You used to know everyone. Now there are all sorts of people moved in. One of the newcomers Scotch he is, brings us boxes of vegetables. There’s also the footpath that goes up past the house. People take their dogs for a walk up there. They’ll always drop in or lean over the wall for a chat.”

“We don’t need any more help,” Doris says, reflecting on the level of support they receive. She pauses for a moment and then adds, “Not at the moment anyway.” It is clear that Doris is aware how vulnerable they are; and how dependent George is on Doris.

### Social life and interests

Before his stroke and heart attack George had been a keen gardener. The house has two large plots of land with magnificent views. George’s two sons help with the gardens now. “I also had a field with a few sheep in. And the bees. I had bees for 20 years or more,” George told me excitedly. “I never were stung; not once,” he said proudly. George had also been active in the village community. He had been the head bell ringer in the village church, had been a church warden and had also been a member of an organisation similar to the Freemasons.

Doris enjoys playing bingo. She used to go to the local main town with her friend in the village. “She’d drive me. She’s nearly 90, but can still get around. We’d go up there all the time.” However, for the last six or seven months Doris hasn’t been going out as much. “Around Christmas I went down with something. I’ve never had a flu jab and I must have picked something up. I didn’t go to bingo for a few weeks and then I got out of the habit. I suppose I should start it up again.”

### Technology

Doris worries about George when she is out of the house. “He could have another fall. He can’t use the phone. He can’t hear. When he picks it up he doesn’t know who it is and hangs up.” She would like him to have an alarm, so if he fell he’d be able to get help. “I don’t know how to get one. Who do I ask?” This fear of George not being able to contact anyone if he has a fall is one of the reasons Doris is going out with friends less than before.

Doris and George have a flat screen television, but do not really like watching TV. George watches Songs of Praise, rugby and Formula One. He likes to watch cricket, but complains that it doesn’t seem to be on television any more. They have three phones in the house – one large numbered BT phone and two walk about units. George can’t use the phones because of his hearing problems. “Can you get louder phones for older people?” Doris asks. Doris talks to a lot of her friends on the phone and has a mobile phone. She only uses this for phone calls. Doris has a pay as you go account with Orange and is able to buy cards to top up her account.

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They do not have a computer in the house and see no need for it. Doris explains that she doesn't understand computers: "All this technology business is too complicated. The changes that have happened since I was growing up I find too much."

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## 5.9 Marjorie and Harold's story

Marjorie has lived in the same village in the South West since she was 14. She is 80 now and her husband Harold is in his 90s. They are happily married, "We have never had a shouting match or a row."

The couple bought the plot for their house 40 years ago. "People are so friendly here. The neighbours are good old-fashioned neighbours." They both want to stay living at home for as long as possible. "It is important to us to stay here at home. We want to die at home. This is where we want to be."

### Family

The couple have two children of their own and have looked after two children from their wider family. They have very many grandchildren. "Most of them live around the county." They can't remember how many great-grandchildren they have. "We've lost count. The last one was born in April."

Their daughter is a teacher in a nearby town and their son is a farmer. They see their children and grandchildren "every week or so. They're busy people with their own lives." Marjorie keeps in touch with their grandchildren by email: "I've got to keep my brain alive."

Marjorie started working at a local solicitor's office when she was 16. Shortly afterwards she met Harold. They started going out properly when she was 17. When she was 18 they were married and have been happily married ever since. "We are two lucky people we have each other." After getting married Marjorie gave up work to look after the children. Marjorie returned to work when her children were older.

Harold was in the army and he was shell-shocked after fighting in WW2. Marjorie says: "He was very brave but he is silent and he doesn't talk about it. He has the same attitude now. Harold is content and that helps me. He never complains." After the war Harold ran a shop in the local village until he was in his 40s but it closed due to competition. After that he worked in another local shop until his early 60s when he was made redundant, and found it hard to find work after that.

### Medical background

Marjorie had a mild stroke in her late 30s. "It wasn't very bad, thankfully." Since then Marjorie has had numerous other health problems. She has had several heart attacks, very bad kidney problems and she is almost blind in one eye. She is also doubly incontinent, as is Harold.

The most troubling of Marjorie's health problems is her severe arthritis. She is often in terrible pain. "I am in so much pain I don't know whether it is Easter or Christmas. I get depressed. It's constant." Marjorie often goes several nights in row without going to bed because of the pain. She stays in her chair, which she finds more comfortable than her bed. Marjorie says that the day of the visit is a bad day. "There is a pain going from my bust to my hip. A good day is when I have hardly any pain. I thank God."

Harold is also in a lot of pain as "both of his knees shattered". Harold can't hear or see very well and he needs a new hearing aid as his current model isn't working properly.

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He often doesn't hear what has been said around him. "I get lonely when he doesn't hear me," says Marjorie.

Marjorie says it is very unlikely she will walk again and they are almost certain Harold will never walk again. But she keeps praying. "I keep telling myself it is mind over matter and I try to ignore the pain." She knows there are those worse off. "But sometimes that is not a great deal of comfort. When there is no escape from it."

When Marjorie is in severe pain Harold plays her tapes with birdsong. "I close my eyes and we travel. I just curl up in a ball. Harold finds me a nice programme on the TV."

Marjorie takes a lot of medication for her various ailments. Sometimes she finds this difficult; because of her sight she often drops things. She takes 12 tablets in the morning, 4 tablets in the afternoon, 4 tablets in the evening and 9 tablets before bed. She overdosed once when she took 12 tablets in the afternoon as well as in the morning without realising. "There's a lot to keep track of and I forget." Harold takes a diabetes tablet daily and painkillers "whenever he feels like it". Their carers arrange their medication.

## Carers

Harold and Marjorie looked after each other for almost ten years but after Harold started to have problems with his legs they required extra support in the home. Harold says when his knee problems started, "the end of life started".

They now receive support from carers seven days a week and it's been like this for the last 15 years. Their care is organised by social services and they pay for it themselves. "We desperately need them. Physically we couldn't get by without them."

Marjorie and Harold are happy with the care and support they receive, but this was not always the case. They have previously had some bad experiences with carers. "They were very unkind. They used to try to rush us. They were cruel. So we changed them. We can't be hurried."

Two female carers come every morning to bath, wash and dress them. They prepare breakfast and get Marjorie and Harold seated for the day. They both sit on electric chairs (designed to support those with poor mobility). They come back at lunchtime to make a light lunch. The carers cook and prepare food for the couple. The carers return at night and get Marjorie and Harold ready for bed.

For the most part Marjorie and Harold are pleased with their carers and they feel like they have developed a very good relationship with them. "This morning they came in and gave me a hug." The carers have a personal touch and that is important. "They have taken the time to get to know us. They put us at our ease."

But the couple are frustrated by County Council cuts. "Social services want a hammering. They allow 15 minutes for a toilet break and to make lunch. Our carers are good but we need more time with them and time means money." The couple say it usually takes a lot longer to help them use the commode and prepare food. "We need more time. They are lovely girls but always in a rush. Things like the Olympics are such a waste of money when you see how some people are suffering."

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The last time Marjorie came out of hospital, she says that the support from the carers was “invaluable. We wouldn’t have survived without them”. But they needed someone to stay overnight for about a week and it cost them much more money. “We paid for it because it was a necessity. We could not have stayed here alone but it’s tough, we just don’t have that sort of money.”

It can still be difficult for the couple to accept that they need this level of care. “We don’t want to feel like a nuisance.” Harold finds it particularly hard sometimes, “It’s undignified when you’ve got to have someone wash your bits and pieces.”

Social services don’t pay for cleaning and shopping so Marjorie and Harold arrange this themselves. The corner shop and local butcher deliver free of charge “which is a huge help”. The couple have a housekeeper who comes to clean the house. She has been their housekeeper for over thirty years. “I know it’s a lot of money but I really can’t afford to lose her. She is my rock.”

## Hospital

Marjorie was last in hospital a couple of months ago after a heart attack. She had a stomach bleed while there and she begins to cry as she talks of her experience. She says she was treated badly: “I swore I would never go back. I was treated like an object. I was very happy to be home.” She was left lying in a pool of her own blood and faeces overnight. This resulted in several complications and infections, including thrush. When she came home she still hadn’t been cleaned properly and her carers had to do it.

Marjorie and Harold both praise the wonderful team of district nurses who helped them during the recovery period. “They are a wonderful team. They can deal with anything.”

Marjorie sometimes suffers from panic attacks and when she returned from hospital she was feeling very anxious. She says that she would like someone to talk to and to listen to her. “I would like to talk to someone to let them know how I am feeling, someone who tries to understand me. Some people come and they just don’t want to deal with the problems of invalids.”

Marjorie has to return to hospital for an eye exam. She says she is “dreading it” but that she doesn’t have to stay overnight. The doctors are also recommending that she has an operation on her toe but Marjorie is against this as it means more time in hospital. “I don’t see the point, I can’t walk anyway and I don’t want to go back there.”

She feels very strongly that she doesn’t want to go back. “If I get another heart attack I want to be let at home to die. If I die I know Harold will understand.” Harold nods. “I have told Harold the next time I have a heart attack he is to leave me – I don’t want to go back to that hospital.”

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## Services

Marjorie and Harold have “great faith in the NHS”. The couple feel like they have a very good community health service. “The GP service is amazing; very responsive. I feel like I can ring any time, there is always someone helpful and polite.” Marjorie says that “even the girl on the reception is very sweet and sensitive”.

Marjorie and Harold try to deal with their illnesses themselves as much as possible but they still see the GP a couple of times a month: “We can rely on him. When we go to the surgery if someone sees us in a wheelchair they help. You couldn’t find fault, if you want someone to come they come.”

Weekends are difficult and they find that they cannot always access the help they need. There is a doctor on call but this service is not always as responsive as they would like. “Weekends are long. Things happen on a Friday night and there is no one there to call.”

The personal relationship they have with the GP is very important and has helped them get through some difficult times. “I feel like a very important person to that practice. Our GP is interested in people. He is a human being as well as a doctor – I can talk to him about anything. Talking to him takes some of the fear of pain away.”

“It’s not always the same in other places. Or in even in places not far away.” Marjorie’s cousin lives only a couple of miles away, and is not at all happy with the care and attention he receives from the GP.

## Mobility

Marjorie and Harold have spent most of their time at home over the last few years. “We were independent. We could get up and make a cup of tea. But when they take away your legs they take away your life.” It takes two grown men to carry Harold down the stairs from the front door and one other to help Marjorie. They usually take the ambulance to get to their hospital appointments. The carer will sometimes take Marjorie to the market in her wheelchair and she really enjoys this. “We long to go out. We feel a bit isolated. We can go days on end without seeing people apart from our carers. I suppose we have each other and that is important.”

Even within their own home they can’t move that much. “We don’t do a lot for ourselves. We try. But it is hard.” Marjorie can’t go upstairs as often as she likes. The pain prevents her. She is not allowed even if she could; if she falls nobody will hear her.

They applied for a grant for a chair lift for the stairs but their request was unsuccessful. Some builders quoted them thousands of pounds to do the job, which they couldn’t afford. They moved the bed downstairs into the living room where they have slept for the last two years. They also have a commode in the sitting room.

Harold has had three or four bad falls. They can’t remember the exact number. On one occasion Marjorie was helping him off the commode – she has to at night when there is nobody else, as they can’t afford full-time night care. Harold collapsed and was unconscious for 15 minutes. It took the paramedics 20 minutes to arrive.

It is Harold’s birthday soon and their son was planning a birthday dinner at his farm. However, they won’t be able to go as they can’t get Harold out of the house. The taxi

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driver will take him but they just can't get him out of the house. "We just don't have enough money to get Harold out of the house."

"Sometimes the boredom is incredible," Marjorie explains. Some of her lady friends who are still mobile "pop into say hello and have a chat". But it is not the same for Harold. "Men have a different attitude to this sort of thing."

Marjorie and Harold have been members of the church all their lives. They were previously Sunday school teachers and had set up a youth club. Because of their mobility problems they can't attend any more. They are regretful that the church is no longer an important part of their lives.

### Leisure and social life

Marjorie and Harold had very active social lives when they first retired. "When we retired we always thought we would have all the time – but we didn't." They used to go dancing two or three nights a week. They loved walking in the countryside. "We have walked every inch of Exmoor. We loved the outdoors, but not any more."

They both enjoyed gardening but they are not able to do it any more. They have a gardener now who comes to take care of the garden. "We just sit and watch now," Harold says regretfully. But their gardener is also a preacher and he comes and sits with them and reads the bible. "This gives us great comfort."

Marjorie has always been creative and when she retired she took regular classes at night school, including art, pottery and upholstery. She liked to paint but hasn't been able to for a while. But she still enjoys making birthday cards, anniversary cards and is starting to decorate Christmas stockings for her grandchildren.

Marjorie is very conscious of trying to keep her mind active. When she was 60 and Harold was in his early 70s they both joined the Open University to learn Russian. "It was fun, it was so different." More recently their daughter has just completed her Masters degree and Marjorie helped her daughter a lot with some of the research. She summarised books and looked things up on the internet. "I really enjoyed it." Their daughter was trying to encourage her mother to do a Masters degree. But Marjorie isn't sure there is any point, "If I was in less pain my brain would be freer and maybe then I would be interested."

They couple like their neighbourhood and they feel very safe and secure there. Being housebound has limited their interactions with neighbours. When a new neighbour moved in Marjorie took it upon herself to send them flowers to introduce herself (as she couldn't walk) explaining that they are housebound and couldn't walk but that they have an open door. Since then they have developed a "lovely relationship" with their new neighbours. They pop in for a chat and bring newspapers and magazines.

The couple listen to the radio a lot. Harold likes watching sport on TV. "We have all the sports channels. I love the cricket and the horse racing and the rugby." They also watch the ballet and the opera. "There was a whole week of Gilbert and Sullivan. That was great."

Harold also watches the news but it often frustrates him, "I want to do something about it when I see what is happening in the world. If I was 20 years younger I would be chained to a railing or something."

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Harold and Marjorie also have a Nintendo Wii and they really enjoy playing it. It used to belong to the grandson and he gave it to them when he got a new one. They like to play tennis and a fishing game. Harold's favourite game is the bowls as he used to play, while Marjorie talks enthusiastically playing about golf on the Wii even though she had never played before.

## Technology

Marjorie in particular has embraced new technology with gusto and she uses it in many different ways. They have a broadband internet connection, a photocopier and a laminator. Their grandson, who works in IT gave them a present of the computer and installed it about 8 years ago. He gave her a "how to use a computer for idiots book" and she has followed it step by step. "It was fool proof."

Marjorie keeps in touch with her grandchildren using email and Skype. "It's company, I feel close to them." She is also on Facebook and is friends with her children and grandchildren. "It is a lot of rubbish," she admits. "I am just on it to be nosy. I go on to see what they are up to."

They use online banking and sometimes shop online. Marjorie likes using Ebay. "I like looking around. It's like window shopping." However, Marjorie is also aware of the downsides: "The internet and health is a mistake. I started looking things up on Google. I looked up osteoporosis. I wished I hadn't. I was already worried but that really frightened me. It was scary." The computer is upstairs and now Marjorie can't go upstairs, except when the carers are in the house but that is never long enough. "I miss it."

They both use the landline and they rely on it. They have lots of cordless phones, by their beds and by their armchairs. "Contact of any sort is vitally important to us. It's a comfort knowing its there. We couldn't do without it." Marjorie has a mobile phone. Harold doesn't. "I use it to text the children and grandchildren but it is difficult to see the screen."

Both Marjorie and Harold wear alarms around their necks. "Even if you don't use it you feel safe." If they press the buttons, the paramedics are summoned.

## Death and dying

Bereavement is a common theme of conversation for Marjorie and Harold. They have a stoical attitude in the face of death. "We are coming to the end now. We have accepted death now." They have lost many family members and friends to old age. And Marjorie says having to deal with all of this makes her feel very low. The couple have talked openly about death with each other but not with their children. "If one of us goes before the other it would be like being cut in half. Maybe Harold would survive but I wouldn't."

Marjorie experiences severe pain with her arthritis and worries that death just means more unbearable pain. "Death doesn't frighten me; dying does," she says.

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## 5.10 Patrick and Liz's story

Patrick is in his early 70s and Liz is in her mid-60s. Originally from London, they moved to the South West over 20 years ago as they weren't happy in London. They have lived in the same two-storey, terraced house since. They enjoy living in the South-West: "The neighbours are lovely. It's so different to life in London. It's better."

They have a large family, and one grandchild lives with them. They decided to move to the South West as it seemed "safer for the kids, a better quality of life". Their children are now grown up. One child lives "up the road," another close by and the rest live "all over the country". One child who lives in the South East comes once a month to stay with them. They also have many grandchildren and a great grand child. They have a close relationship: "We turn to each other first, then to our children. Our son pops in most days."

Patrick and Liz met and married in London. "We made a good choice with each other. Liz is the most important person to me."

They talk affectionately about their life together in London. Patrick says, "I loved my work. I made great friends." Liz also worked in London. She stopped working when they had children. However, when they had grown up she went back to work managing a nearby pub at the weekends. Patrick was great. "He always looked after the kids when I was working. I could always depend on him."

Leaving London was hard for both of them. "I love London, my life was there, my friends, family. But the doctors told me that I should live in a quiet place because of my diabetes." Despite trying, Patrick failed to find work when they moved here. "This was stressful. But in every other way we settled in well."

### Patrick's health

Patrick has diabetes. He had a stroke 10 months ago. He was at home in the kitchen and he had just had a bite to eat "and then he just sat there. He didn't move. He didn't know who I was, he didn't know his own name or where he lived." Liz called the paramedics and they took him to hospital immediately.

When Patrick was in hospital he had a colonoscopy and the doctors discovered that he had prostate cancer. He had a successful operation to remove the cancer. At the same time he also had a hernia operation. He is now incontinent due to his cancer. "Since I have been sick life has taken a different shape. I have different needs. The things I used to worry about seem petty now."

### Hospital admissions

Patrick and Liz say that for the most part the surgeons who were in charge of Patrick's cancer operation "were very good at explaining everything. We had good communication". However, while in hospital Patrick ended up with several infections including MRSA. He had a heart attack in the hospital but there was "terrible miscommunication about this." The doctor told Liz that Patrick had fainted and the nurse told Liz that he had had a heart attack.

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Liz found travelling to the hospital to visit Patrick very difficult. Even though she had to take two buses she went everyday. “If I missed the bus I missed my visit.” Patrick went to recuperate in the community hospital nearer to home and this was much better for everyone. Since his stroke Patrick has had also had two further heart attacks and has had to return to the hospital.

Both Patrick and his wife describe his time in hospital as “awful”. They are both in tears as they describe Patrick’s experience in the hospital. Liz says: “I had to fight with the doctors and nurses. Patrick always says its ok. He accepts it. He doesn’t complain about the pain, about how they are treating him. But I will.”

There were not enough staff to help him to the toilet so they had to put a catheter on him. The staff didn’t change his clothes. Patrick was very weak – so Liz came to change his clothes everyday. “Nobody was showering or washing him and he was incontinent with MRSA. The bed was often soiled as the catheter hadn’t been put on properly.”

Liz says she “went nuts when I saw the state he was in. They should have acted immediately. It’s not bloody good enough. Someone must have seen him.” Liz says she “stripped the bed in horror. I went screaming to the nurses and they put the bedding in the basket, brought me some new bedding and she said ‘you can do the bed.’” The day after Liz went back to the hospital and Patrick was sitting there needing to go to the toilet. Nobody would take him so Liz had to take him. Liz had to clean and strip Patrick. When the nurses were dressing him they sometimes put pads on the wrong way and he was often left sitting in soiled pads. Liz had packed and washed clothes for Patrick but the nurses wouldn’t dress him in his own clothes. “Everyday I went there was something. If he dropped some food nobody picked it up. I had to clean the floor.” Liz complained several times to the nurses and the doctor. Patrick says he was so ill he just didn’t have the energy to complain.

While Patrick was in hospital he was required to travel to their local regional centre for special heart treatment. His wife asked the doctors and nurses to let her know, to give her a call by phone and tell her when he would be taken there. Patrick asked the doctors to tell his wife. Next thing he knew he was taken to the regional centre but nobody had told Liz or the children. It was the one day that Liz had not travelled to the hospital to visit Patrick, as she herself was not feeling well. She had phoned in the morning and everything was fine, she had phoned in the afternoon and everything was fine. However, when her son phoned at 7pm and he had been moved. “What would have happened if I went up and didn’t see him in the bed?”

Patrick and Liz are very fearful of hospital experiences: “I live in fear of him being sent back in there.”

## Recovery period

Liz “couldn’t stop crying after Patrick’s stroke. I didn’t know what was going to happen”. She has had her own health problems: sciatica, arthritis, angina and she has had three heart attacks. While she is now Patrick’s primary carer, he had looked after her when she had her heart attacks. “Now we have swapped.”

Since Patrick’s stroke he has been engaging with a range of services. They rely heavily on their GP. “We can’t fault the local doctors. We can just call them up and talk to them. They are very helpful.”

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Carers come every morning and evening to help with washing and showering, getting dressed and preparing for bed. They often give advice and guidance and suggested, for example, that the couple could get yellow bag collections for incontinence pads.

They are not paying for Patrick's care and generally they have been happy with the service they receive. However, there were some initial problems. The social care plan was wrong at first. "We couldn't understand it with jargons and acronyms and some of the details of Patrick's illnesses were wrong. It was a fight. I had to phone three times to get the plan for Patrick right."

Both Patrick and Liz have to take medication every day: in the morning, lunchtime and evening. Liz gives Patrick his medication and sorts it all out. "It takes me one hour every two weeks to sort out it all out."

The district nurse visits Patrick regularly. Their son and daughter-in-law live nearby and help out, as do their neighbours. Even with this help, Liz worries that she isn't doing enough. She says that since Patrick has been very sick she feels neglectful of the housework. But their granddaughter helps out a lot, as does their daughter in law who lives nearby. "The children are worried about Liz and how she is coping."

They get a lot of useful information from the nurses in the community hospital. Patrick spent time recuperating there. They aren't sure what they are entitled to get for free. Initially they weren't told that they could get waterproofs for free so they bought them. "But sometimes I don't know who to go and ask. I go to the doctor."

Liz says there is someone coming "to help us sort out the benefits. I get so confused with all the forms. It's hard to know what to do".

Someone always has to be with Patrick and he hasn't been out of the house often since he returned home from hospital after his stroke: "I have no social life. We spend most of our time indoors. My body isn't ready for it."

It has been difficult for Patrick to get used to being completely dependent on others and having his independence taken away. "You take things for granted. You don't realise until things happen. You can't walk up the street any more. You have taken life for granted."

## Mobility

Patrick's movement is severely restricted. He can walk around the house with the aid of a walking stick but can't go up or down the stairs without his wife coming with him as he might fall. "I need to be with him all the time. He can't move without me."

His eyesight is bad and he often trips over things. The only toilet in the house is upstairs. "The most difficult thing is not having a downstairs loo." They keep a commode downstairs just in case. Sometimes Patrick has felt too unwell to go upstairs to bed and has had to sleep downstairs. "When he sleeps downstairs I worry he'll take a turn for the worse."

They have installed a walk-in shower. Patrick had slipped in the bath a couple of times and they were fearful that it could happen again. "Social services have been very helpful. They sorted us out. They put the wet room in the bathroom. But they are slow."

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The occupational therapist came to the house and has suggested that they install a chair lift. They are waiting for someone to come around and access their situation but they are not sure what is happening or who is taking responsibility: “We are waiting for the occupational therapist to come back from holidays.” It can be frustrating and uncertain not knowing what is happening: “I’d like if we could rely on people to do something when they say they will – like getting a stair lift. We don’t know what is going on and nobody is telling us.”

Liz is very proud of their colourful and pretty garden but since Patrick’s stroke he has not been able to get outside because of the steps. They have recently installed special railings and a ramp so that he can enjoy spending time there.

For Patrick getting out of the house is also a challenge. “Being indoors all the time is frustrating for me. I don’t want to sit here all the time.” Liz doesn’t drive and as they don’t have a car, they are dependent on neighbours and their daughter and son-in-law. Sometimes they take a taxi and go up to the market for a cup of tea and cake. Patrick complains that it feels strange for him to be waited on. He also takes a taxi to see the doctor. Sometimes the taxis are subsidised; sometimes they get lifts from friends and neighbours but they always pay for the petrol.

With all of the difficulties Patrick faces moving around inside his house, the couple had considered moving into a bungalow. “We got the forms but then Patrick wanted to stay. He didn’t want to move.” Patrick says “I am much happier to stay here. I am not bothered to move. We talked to the doctor and he said ‘Stay where you are and get a stair lift.’ The stress of moving would have tipped us over the edge.”

## Leisure

Patrick used to love going to the pub to see his friends for a pint. Patrick and Liz would often go out for a meal with their children and take day trips to Exmoor. But this doesn’t happen as much as they would like. “We try to for special occasions. We went for a big family do for Liz’s birthday.” Usually Patrick would have baked a cake but he hasn’t done this for a while.

A couple of years ago Patrick and Liz saved up and went to Corfu on holidays. Their daughter and son-in-law arranged everything. They really enjoyed the holiday and “have lots of happy memories, especially the Elvis impersonator from Albania.” They had booked a holiday for this year to back to Corfu with their granddaughter, daughter and son-in-law. However, they had to cancel because of Patrick’s health. They have rebooked for next year. “This will give Patrick a whole year to rest and get ready.” Patrick says that the prospect of going on holidays with the whole family is giving him something to get better for.

They have no contact with voluntary organisations and have no appetite to get involved. “We’re not interested in all that volunteer stuff.”

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Liz used to go to the craft club once a fortnight but stopped to look after Patrick.

“There is no time for going to things like that now.” – although she still tries to make birthday cards for family members if she can.

They have lots of films and DVDs. They recently got rid of Sky because they weren’t watching it.

## Technology

Liz has a mobile phone she uses it to text the kids and call her siblings who live around the country. However, they have poor mobile reception where they live. Patrick has never had a mobile but uses the landline a lot: “He is always on the phone to his sister. We never get to see them now. She has caring responsibilities too and it’s such a long way away.” The telephone is in the living room and it has big red buttons for the visually impaired. They are thinking of getting an extension and putting it upstairs so that Patrick can use the phone when he is upstairs. “It’s hard to get up and down the stairs quickly when it rings.”

They have a desktop computer that they bought second-hand from a friend. Their granddaughter taught Liz how to use it. “I was wondering what our granddaughter was spending all her time doing. She said ‘Googling.’ I thought I had to find out what Googling was.”

Liz uses the internet to buy things and finds specialised items for Patrick - clothes, shorts and shirts. He needs them in a bigger size as he has to wear pads and Liz couldn’t find them in the shops. “I bought them online and they were delivered the next day. It was easy.”

Liz is on Facebook and she finds it a good way of keeping in touch with friends and relatives. “It’s an inspiration to keep in touch. Especially since Patrick has been sick we’ve missed out on a few special occasions but it’s lovely to be able to see the pictures. You don’t feel you have missed out as much.” Liz often prints out pictures so that Patrick can look at them properly.

They don’t do online grocery shopping. “I would sooner go to the shop. I like to see what I can get.”

## Good days and bad days

“Getting Patrick right is my priority,” says Liz. “As long as Patrick is ok that is all I am worried about.” She says that she has a bad day when she “just can’t figure things out. When it all gets too much and gets you down.” Patrick says a good day is “when I am laughing and joking again. When I am not worrying about Liz worrying.”

# Appendix

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# 6

## Best practice ideas to stimulate service development

The stories detailed in this report highlight many of the policy and service challenges that we will face as our population ages. It is clear that new services and approaches are required to improve the lives of people as they grow old and to make the most of the resources and opportunities that are available within communities. We wanted to include a range of new ideas, services and approaches that are emerging from around the UK and internationally. These are just a few of the innovations that are out there and are intended solely to stimulate debate and new thinking.

*Idea 1*

# The Silver Car Club



## The challenge

- As people get older they often have to give up driving.
- This can isolate older people (especially in a rural setting), but taxis are too expensive for many.

## The Silver Car Club concept

- A new way to get out and about for the over 60s...
- Join the Silver Car club and for a small contribution to the scheme you can access safe volunteer drivers who are going your way. You both get to make new acquaintances
- All the drivers are vetted so you can be reassured you'll be safe and sound.
- And all you need to do is contribute something to the cost of the petrol. It is all prearranged and agreed so no cash changes hands and you will know what it costs.
- Get out and about again – and help someone else with the cost of their trip too.
- And it's greener...

## Example organisations offering similar services:

ITN America - Independent Transportation Network in the	<a href="http://www.itnamerica.org">www.itnamerica.org</a>
Liftshare – the UK's largest car sharing scheme	<a href="https://carshare.liftshare.com/">https://carshare.liftshare.com/</a>

## Questions to consider in your own local co-design:

- A dedicated door to door service, or a lift with someone going the older person's way?
- Free service or contribute to petrol or pay for lift?
- Could people develop credits to be driven themselves through volunteering?
- How to attract volunteer drivers?
- How to vet drivers? (Is this needed?)
- How do older people who don't have access to the Internet find their ride? (Through their carers? Through other organisations? Through other volunteers?)
- What happens in bad weather? (Four wheel drive registry?)
- How to make this happen: Set up a new service? Develop an existing one? Ask an existing provider to set up in your area?

*Idea 2*

# Share My Garden



## The challenge

- As people get older it can be hard to keep a garden the way they used to.
- This is frustrating. At the same time many people love gardening, want to grow food but don't have a garden of their own"

## The Share My Garden concept

- A new way to keep your garden looking good and share your love of gardening.
- As a member of "Share My Garden" you are matched with someone local who loves gardening and who wants to grow their own food but doesn't have their own garden. Together you agree how you will manage things, when they will visit, what fruit and vegetables will be grown etc
- All you need to do is to be happy to share your garden with someone who is also enthusiastic about gardening – and be open to some new ideas.
- See your garden bloom again and share your own knowledge and expertise.

## Example organisations offering similar services:

Garden Partners (Age Concern Wandsworth)	<a href="http://www.ageuk.org.uk/wandsworth/Our-services/Garden-Partners/">http://www.ageuk.org.uk/wandsworth/Our-services/Garden-Partners/</a>
Worthing GardenShare	<a href="http://transitiontownworthing.ning.com/group/worthinggardenshare">http://transitiontownworthing.ning.com/group/worthinggardenshare</a>
Landshare	<a href="http://www.landshare.net/about/">http://www.landshare.net/about/</a>

## Questions to consider in your own local co-design:

- Is gardening a core need for older people in your area?
- Are there enough people in the community who want to garden or grow their own food who don't have their own gardens?
- Do you want to focus on growing food (with a requirement to give up part of the garden for fruit and vegetable) or move the focus to supported gardening (flowers) as a companion activity?
- Should those involved be required to sign a contract, or is it up to those who are matched together to decide if they want this?
- Do gardeners need to be vetted?
- Could the administration of "matching" also be done by volunteers or does this require a paid worker to facilitate?
- Should older people pay for core gardening materials or share the cost with the volunteer gardener?
- How will non-internet enabled older people find this service? (Through their carers? Through other organisations? Through other volunteers?)
- How to make this happen: Set up a new service? Develop an existing one? Ask an existing provider to set up in your area?

*Idea 3*

# Clever connections



## The challenge

- As people get older they can end up isolated from their community. At the same time they still want to contribute something back.
- Other community members want to connect with older people but have limited time.

## The Clever Connections concept

- A new way to give something back and meet more people in your community.
- Join this club as an older person and you get to support and coach a young runner in meeting their goals to increase fitness. And you both get to make a new acquaintance. Every week a local runner will pop in as part of their running routine to say hello and possibly give you a hand with something you need. Your role is to provide encouragement when they turn up!
- And all you need to do is sign up and maybe put the kettle on...

## Example organisations offering similar services:

The Good Gym

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

## Questions to consider in your own local co-design:

- What is the equivalent connection for your area? Is it running or something else?
  - Dog walking
  - Running
  - Pop in on way home from commute
  - Etc....
- Do the volunteers need to be vetted?
- Who will run the portal to engage volunteers?
- How will non-internet enabled older people find this service? (Through their carers? Through other organisations? Through other volunteers?)
- How to make this happen: Set up a new service? Develop an existing one?

*Idea 4*

# The Timebank



## The challenge

- As people get older they can end up isolated from their community. At the same time they still want to contribute back.
- Other community members want to connect but have limited time.

## The Timebank concept

- A new way to give something back and meet more people in your community.
- Everyone has valuable skills and experience to share. Join your local Timebank and you could be swapping your time and knowledge for everything from a language class, a trip to the shops, some handy DIY or gardening advice, or a free session at the local swimming pool. The only limit is what you and others in the community have to share.
- And all you need to do is sign up to the local Timebank at your local GP surgery. You can put in as much or as little time as you want (the minimum is just an hour) and gain credits to spend how you like.

## Example organisations offering similar services:

Care4Care	<a href="http://care4care.org/">http://care4care.org/</a>
Spice	<a href="http://justaddspice.org/">http://justaddspice.org/</a>
Timebanking UK	<a href="http://www.timebanking.org/">http://www.timebanking.org/</a>
Rushey Green Timebank	<a href="http://www.rgtb.org.uk/">http://www.rgtb.org.uk/</a>

## Questions to consider in your own local co-design:

- How will you motivate your community to join the timebank?
- Where will your community be most likely to engage with timebanking? (Via an existing voluntary organisation, through their GP or through a new timebank?)
- Do you have specific ideas you think timebanking will help support, or do you want to let the timebankers develop their own schemes?
- Is there any existing timebanking already in your area you can build on?
- How will non-internet enabled older people find this service? (Through their carers? Through other organisations? Through other volunteers?)
- How to make this happen: Set up a new service? Develop an existing one? Ask an existing provider to set up in your area?

## Idea 5

# Share My Home



## The challenge

- Older people (like everyone else) want to stay in their home but as they grow frailer can suffer from isolation when living alone or struggle to complete the tasks of daily life.
- Many people are finding it difficult to find affordable housing.

## The Share My Garden concept

- A new way to stay in the home you love affordably
- If you want to wish to continue living independently in your own home – but are finding you need some extra support for some things – why not offer a free room to an individual in exchange for help around the house, shopping and company (usually 10-20 hours per week).
- The Homesharer will be vetted, the two of you carefully matched and a contract agreed. You remain independent and have the satisfaction of a mutually beneficial arrangement – your Homeshare might be a student looking for an affordable way to study, or a worker relocating from another area.

## Example organisations offering similar services:

Shared Lives Plus	<a href="http://www.sharedlivesplus.org.uk/">http://www.sharedlivesplus.org.uk/</a> (gives advice for commissioners and a good practice guide to setting up HomeShare schemes)
Wesley Home Share (Australia)	<a href="http://www.wesley.org.au/agedcare/wesleyhomeshare.html">http://www.wesley.org.au/agedcare/wesleyhomeshare.html</a>
East Sussex County Council Homeshare scheme	<a href="http://www.eastsussex.gov.uk/socialcare/carers/homeshare/default.htm">http://www.eastsussex.gov.uk/socialcare/carers/homeshare/default.htm</a>

## Questions to consider in your own local co-design:

- Is there strong demand for housing in your area and a good transport network (which might make the HomeSharing concept attractive)?
- In your area would a student-led scheme work best, or a more open scheme (including those leaving home, people new to the area etc)?
- How will the homesharers be vetted?
- What will the cost of administration of “matching” be and how will this be funded?
- How will you market the scheme?
- How will non-internet enabled older people find this service? (Through their carers? Through other organisations? Through other volunteers?)
- How to make this happen: Set up a new service? Develop an existing one? Ask an existing provider to set up in your area?