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Well-being in old age: findings from participatory research

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Addendum

This research was conducted in collaboration with Age Concern Brighton, Hove and Portslade. At the time of going to print the organisation was on the point of joining Age UK and changing its name to Age UK Brighton & Hove. Any references in the report to Age Concern should be understood as Age UK Brighton & Hove.

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Executive Summary

Introduction

Well-being has become an important focus for health and social policy in general, and in relation to older people in particular. Well-being has been linked to ideas about 'active ageing' (The National Framework for Older People DH, 2001) as well as independence (Opportunity Age DWP, 2005). The connection between well-being and independence was reinforced in the social care Green Paper, Independence, Well-Being and Choice: Our vision for the future of adult social care in England (DH 2005).

But what is well-being? Can it be measured? Does it mean the same to everyone? And what produces well-being? Researchers have come up with different definitions and 'indicators' to be used in measuring well-being and these sometimes produce rather different results. Some research and policy appears to assume that well-being is a quality of individuals and can be produced through individual effort.

Others have argued that an emphasis on the individual does not sufficiently take into account the importance of relationships between people and that, rather than measuring individual well-being, we should focus more on how to generate caring relationships that can enhance well-being.

This project was designed to develop our understanding of what well-being means to older people, and of how it is produced. An important aim of this project is to make a contribution to thinking about policy and practice and how this might enhance or detract from the way people experience well-being in old age. Our aim was not to measure, but to develop insight into how older people sought to maintain a sense of well being, often in circumstances where this was difficult; what helped them do this and what got in the way of 'being well.'

As we describe in section 3 our approach soon became one that understood well-being as profoundly affected by the nature and quality of different types of relationship, rather than an individual characteristic or quality. Thus, as well as looking at other work on well-being, we have also drawn on work exploring an ethic of care in order to understand what affected older people's experiences. This work starts from the recognition that human beings need others in order to survive and flourish. It identifies the universal need for care and explores the ethical as well as practical meanings of care giving and care receiving.

Our approach: co-producing knowledge with older people

The well-being project was carried out between 2008 -11 in Brighton and Hove by a team involving university researchers, a voluntary sector manager and older co-researchers. Our aim was to develop participatory research with older people which would foreground lived experiences of ageing and co-produce knowledge about what well-being means. We developed a process that enabled older people (both those who took part as research participants and the co-researchers) to engage in reflection and dialogue about what well-being meant to them and what both contributed to and detracted from being well as they grow older.

We recruited eleven co-researchers who were at the time aged between 60 and 87. A key part of the project has been learning how to work with a group of older people at different stages of later life, as well as from different backgrounds, and trying to ensure that they were able to contribute their own particular strengths. We also aimed to ensure that their involvement as co-researchers was personally worthwhile and rewarding. Right from the beginning we emphasised

the importance of older people as narrators of their own stories and interpreters of their own lives. By working together on the design, delivery and realisation of the research we also aimed to break down barriers between 'expert knowledge' and 'lay knowledge' - between academic expertise and community expertise.

Research relationships

We needed to develop inclusive ways of working that were attentive to the different needs and circumstances of our colleagues. We recognised that involving older people is not just a matter of good design, but of ethical practice. We worked with ideas deriving from care ethics to develop our approach to ethical relationships within the research team, as well as in our relationships to the older people who took part as interviewees or participants in focus groups. Involving our team of older people in research was not just a matter of including them in a set of activities, but was also about the nature of the relationships we developed during the process, and how these were connected to our subject matter and our developing understanding of well-being and ethical research practice. It involved being attentive not only to the different contributions that team members felt comfortable with making, and to the practical support necessary to enable them to work with us, but how we could ensure and hopefully promote well-being through the ways in which we worked together.

Research design, analysis and dissemination

The project was carried out in four phases. The first phase sought the perspectives of those working within Age Concern on what contributes to or detracts from older people's well-being. The values of the organisation emphasise person-centred practice and we wanted to explore how workers and volunteers sought to embody these values in their work, and what aspects of practice they thought contributed to well-being.

The second and third phases captured older people's perspectives. During early discussions on the research design the team rejected using a structured questionnaire to measure well-being and opted for an approach which would capture lived experience in all its contextualised and relational aspects. We developed a topic guide for individual interviews and focus groups to explore what older people themselves consider important. Interviewees and focus group participants were able to shape what they talked about; to reflect on issues that the team themselves might not have identified as likely to be important; and to discuss why things were important to them and what precisely it was about issues that made a difference in terms of their well-being.

The co-researchers carried out one to one interviews with 30 older people and seven focus groups in which another 59 older people took part. Half of those who took part in one-to-one interviews were aged 85 or older, including 5 who were in their 90s. Twenty were women and ten were men. Fifteen interviewees were users of Age Concern services and the others were recruited using snowballing methods to include older people in a diverse range of circumstances.

Co-researchers used the topic guide to help structure the interview and respond to what interviewees talked about. A similar approach was adopted in focus groups where participants were invited to explore and discuss what they felt was important to well-being.

To help us make sense of what older people had told us we identified themes within the interviews and focus groups by developing a coding framework and coding the transcripts. The coding process was undertaken collaboratively by some members of the team. The coded data was then organised into thematic sections and brought to team discussions for reflection and interpretation. The presence of the team's experience, particularly in the thematic analysis, was really important. They were able to resonate with the data bringing an authenticity and an understanding of the meaning of the material from their own lived experience.

The final phase of the project was designed to begin a process of engagement with practitioners and other service providers. When we set out we envisaged the exchange of knowledge and skills as an interactive process, involving developing tools and resources relevant and useful to those working with and providing services for older people, as well as creating links to the wider strategic and policy agenda. As the research was drawing to a close we were successful in securing funding from the Economic and Social Research Council to disseminate our findings to a wider audience and we started this phase of work in November 2011. Older members of the research team have produced a booklet for older people drawing on the research findings and their own experiences.

Thematic findings: Age Concern staff and volunteer perspectives

Ten interviews were carried out with Age Concern staff and volunteers. They explored the main issues for service users and what Age Concern services and culture of practice may contribute to older peoples' well-being. The main points identified by those working with Age Concern were:

- Different levels of care needs tend to relate to age and those over 80 may need higher levels of care. There can be a loss of confidence, lower expectations and a feeling of not wanting to be a burden within the older group of service users. Those aged 50 – 70 are generally more active and have higher expectations around being engaged, participating in activities and being independent.
- Isolation and loneliness are major issues for those accessing care and rehabilitation services. Lack of social contact can be a result of loss of mobility and/or confidence to go out; bereavement and the gradual loss of friends and family can result in an increasing sense of isolation and feeling cut off from the world. For people who are unable to get out, having regular social contact makes a big difference to well-being.
- Needs for support can be difficult to acknowledge and people may be reluctant to ask for help. Staff reflected that often this is linked to a sense of pride and/ or embarrassment. They highlighted the importance of listening and responding to what people say and allowing people to make their own decisions about the services they receive.
- Time was identified as an important factor in being able to work in a person-centred way. 'Being present' with the person, acknowledging their situation and feelings, and building trust, being consistent and reliable were also considered crucial. Staff reflected that the quality of relationships can impact on the intervention and being attentive to small things can make a difference to the person's well-being.

Thematic findings: older people's perspectives

The thematic analysis has been organised in four sections: **people; health, care and support; resources; places and environment.**

People

- Relationships of all kinds emerged as significant in many different contexts - within families, friendships and with neighbours, as well as casual interactions with people in everyday encounters.
- Families can be a source of support and security, but for some can also involve difficult and painful relationships, distance and estrangement.
- Good relationships with adult children can contribute to well being and maintaining satisfactory relationships was recognised as important. This involves learning to relate

to adult children in different ways. Accepting help from adult children and recognising the role reversal between parents and children is a major shift older parents face. A reluctance to be 'a burden' on children was common.

- Role reversals within relationships between husbands and wives where there is a need for care, impacted on identity and maintaining a sense of self.
- Friendships are important and the meaning of friendship may change with ageing. Ill-health and physical distance may make it harder to sustain friendships and the loss of long term friends, with shared experiences and history, was felt very strongly.
- Good neighbours can play a vital role in emotional security and support. A move to a new area or housing situation meant that some did not know their neighbours.
- Everyday interactions with others, such as conversations struck up in shops or on buses can contribute to a sense of being connected with others and the outside world.

Health, Care and Support

- Health featured as an important factor in well-being, but poor health is not necessarily directly related to an absence of well-being. Ill health and managing long-term health conditions impact on relationships and experiences of loss and can cause instability and uncertainty due to fluctuations. It requires adapting, coping and adjusting to the need for help and assistance. Fears of ill health in the future and being taken ill can impact on the present.
- Deteriorating health and disabilities can change the capacity to engage in social life and impact on relationships, particularly on those affected by communication difficulties, such as hearing and speech loss.
- Acute or chronic ill health has not only physical effects, but also emotional and psychological impacts. These include a loss of confidence and self control which can generate a degree of fear, for example of going out alone, crossing roads, and negotiating public space and places. Managing the psychological aspects of ill health, such as fear, anxiety and vulnerability can be difficult if there is no one these can be shared with and are shouldered alone.
- Access to health services and GPs are important. This includes location, appointment times and systems and being properly listened to by practitioners. The quality of the interaction and relationship with the member of staff (whether GP, nurse, receptionist or consultant) is key. Poor services and relationships can feel disempowering for older people who may be fearful of having a service withdrawn or asked to leave a surgery.
- Care can encompass a range of activities and relationships, from having someone watching out for you, help with household tasks, to nursing and personal care. The ways in which care contributes to well-being depends on the ways in which it is given and experienced. Knowing that care is there in the background if needed is important and gives security and comfort.
- It can be difficult to acknowledge needs and accept help. People may be reluctant to ask for help because of not wanting to be a burden or fearing a loss of independence and control. For some there was also a fear of rebuff or rejection. If the request for help and the support received is positive, it lessens the sense of feeling a burden and people can experience well-being from the experience of being well cared for. The availability of information and advice about sources of help, and people's feelings about asking for help often combined to make it hard to find the help needed.

- Both giving and receiving care involve significant emotional aspects, such as changes in self identity, sometimes involving a reversal of a previous role in a relationship and can be difficult to adjust to. Taking on a caring role can have conflicting emotional impacts, for example feelings of guilt and duty as well as satisfaction and love. People can experience well-being through caring for others.
- Those caring for others also need support for themselves. Their own health problems cause concern about being able to continue in the caring role. Carers can find it hard to ensure their own needs are met.
- Participants found that information about services or local authority support was not easy to access and there was some uncertainty about rights and entitlements in relation to social care services.
- Many participants were worried about the cost of care services and expressed anxiety about meeting eligibility criteria, and feared expenses may be beyond their control.
- Concerns about future care needs related not only to cost, but also to the quality of care provided within residential homes.
- When health and care services were underpinned by values such as respect, reliability and reassurance, and where trust was present, the person receiving the support does not feel disempowered or de-humanised as a result. The quality of the service was identified by many participants as important and this included staff skills; time given; flexibility and sensitivity.

Resources

- Being able to draw on experiences gained over a lifetime, learning from past mistakes, or reflecting on the benefit of hindsight, informed present attitudes and was a personal resource for some. Memories and reminiscing can generate a sense of pride at past achievements and positively contribute to self-identity and resilience.
- Faith and spirituality can be important resources which extend beyond attending church and religious affiliation. For some, spiritual and religious life helped make up for loss of other relationships and provide a sense of belonging.
- Learning to adapt to change, making the most of the present and focusing on the ‘here and now’ were identified as important personal resources.
- Being able to think about the future and looking forward, without anxiety and fear, particularly in relation to health and social care needs can be important. Planning for practicalities and having things to look forward to can help.
- Volunteering, having interests and hobbies or belonging to social groups or church communities can help people feel involved in wider society. Having opportunities to be ‘active’ and join in were clearly important, but this may become increasingly difficult with age and frailty.
- Financial resources are important and ‘having enough’ without having to worry both in the present and the future was a common theme. Most people indicated that they managed on their current income (whatever level it was), but for some receiving benefits was crucial in achieving this. The necessity of planning ahead and careful management of income was something learned early on in life by many.
- The increased use of technology creates both opportunities and barriers. New technologies can be a means of communication when physical activity and travel become problematic, and can be valuable for keeping in touch with family and friends living

abroad. Difficulties in learning to use technology and not knowing what to do when things go wrong can create anxiety and contribute to people feeling out of touch or left behind. Many experience frustration with the assumption that everyone feels comfortable with using ICT and some felt at a disadvantage and even penalised if they did not move to online payments methods.

Places and environment

- Feeling safe at home is important and having someone, like a neighbour who will notice if anything is not quite as it should be, added to people's sense of security.
- Keeping the home in good order, often in the face of increasing difficulty due to mobility or health problems, is also important. Older people want to have a degree of control over their living environment. Managing the maintenance of the home was a source of anxiety, particularly for those who live alone. This included difficulty in finding trustworthy trades people to carry out repairs and the costs involved in structural work that might be needed. Concerns about not being able to manage the home and garden may shape decisions to move to a more manageable home.
- Local buses and free bus travel were greatly appreciated. For those with limited mobility or without a car, and who were able to use buses, being able to get to places with relative ease was important for accessing services and keeping connected. Some parts of the city are not easily accessible by bus, particularly the seafront which is a popular area for many.
- Some areas of the city were avoided, due to difficulties in negotiating the crowds, or at night time. Many people are reluctant to go out at night which restricts social life and many highlighted the importance of accessible day time activities.
- Some of the difficulties in getting around the city can be attributed to the physical landscape with its steep hills. This creates difficulty in accessing many areas of the city, particularly for those with mobility problems. But one advantage of the hilly landscape is the views it offers which are important to some.
- The ways in which people spoke about the sea and seafront and other public places, like parks and gardens, indicate that having access to outdoor space can positively contribute to well-being.
- Many described Brighton and Hove as a lively place and enjoyed the cultural life it offers. Being able to go out and enjoy public spaces and facilities as an older person was affected by practical considerations, such as availability of public toilets and seating.
- Having a 'place' in the world as an older person depended on the extent to which needs were recognised and acknowledged on an everyday level, on the ways other people treat them and how they see themselves as older people. How people feel about ageing is not only related to self perceptions, but wider societal attitudes towards ageing and older people.

Narrative analysis

In addition to the thematic analysis seven interviews were selected to undertake a narrative analysis looking at each interview as a whole and the nature of the stories that run through them. This offers ways of understanding how issues such as people's experiences of poor health – their own or that of close relatives; their feelings about Brighton and Hove as a place to live; or their

responses to the social changes taking place around them, interact in the context of their lived lives. They offer an account of well-being that highlights the significance of being able to make sense of life changes over time and thus the need to understand well-being not as a steady state, but as a dynamic process of responding, adapting and negotiating.

Being well through change and loss

- Different narratives emphasised both loss and disruption, and adaptability and resilience.
- The significance of loss of different kinds: those associated with physical capacity; loss of valued activities; the loss of people who have been very important, were key issues. People were learning they could not always 'be the person you used to be'.
- The capacity to adapt, develop new skills and find ways of 'getting through' can themselves be sources of well-being. While this requires hard work in a practical sense of maintaining the circumstances that might be capable of sustaining things that are important to people's sense of well-being, this work of adaptation also involves a substantial amount of emotional labour.
- Changing cultural and social norms are important and the way in which these impact on subjective well-being affect older people in different ways (eg attitudes towards gay men and people with learning disabilities).
- Material circumstances can make it easier to mitigate losses (eg being confident that it will be possible to retain a home that is not only comfortable but enables contacts with the kind of physical environment that is a source of well-being)
- Particular historical moments and events can be significant in providing a benchmark against which to assess current circumstances and experiences (for this generation of older people, their war experiences are often significant).

Caring, being cared for and other relationships

- Care is vital to well-being, but can be a highly ambivalent experience for both care givers and receivers. This is affected by the extent to which care is supported and valued both personally and socially.
- For carers the experience of giving care to, or securing good care for, a spouse, can be fundamental to the carer's own well-being.
- The significance of care to well-being is not restricted to relationships identified as caring relationships. Human interaction, face to face contact and friendship are highly significant.
- The importance of reciprocity and the capacity to care for others remains important even for those with in difficult personal circumstances such as ill health.
- Narratives of relationships and care are both highly personal and reflect important social and cultural influences on well-being. They reinforce the way in which it is not possible to understand well-being as an individual state, but rather how it can be produced in and through relationships.

Recognition, respect and identity

- Being respected and treated properly can positively contribute to well-being.
- Old age and the way it is perceived can bring about a loss of recognition or respect.

The people who spoke most explicitly about the importance of recognition are those whose identities may have been most threatened by others' attitudes towards them.

- Negative perceptions and experiences of loss can lead to internalized feelings of having outlived usefulness in old age.

Discussion: Learning to be 'well enough' in old age

Our analysis has revealed the very different experiences that constitute old age and the varied factors that affect well-being at this stage of life. We know that relationships of different types are important and we know that the resources and capacities that people have to adapt to personal and social changes can make a big difference to people's sense of being well in old age. We know that security, feeling like you 'belong', and being confident that help is there if you need it are all important.

There is a danger that definitions that emphasise physical health, people's capacity to plan and set goals, and to be active within their communities, may exclude from any hope of being well those people for whom old age is accompanied by illness, a reduction in their physical horizons because of mobility problems and who, because of advanced old age, are focused on being well in the present rather than planning for the future. We suggest it is useful to talk about being 'well enough', rather than setting a standard against which to measure older people's well-being.

The stories that people told of their personal experiences of growing older has led us to reflect on the 'work' that ageing entails, and the learning that is necessary to be well enough at different stages of older age. These are processes that require change and adaptation over a period that may be longer than that from birth to adulthood. Both the work and the learning that is required need to be done not only by older people themselves but by us all if the ageing of the population is be experienced collectively as a positive development, rather than a 'problem' to be managed.

Older people learning to be 'well enough'

- Learning to be 'well enough' involves both emotional and organizational labour during the processes of personal, interpersonal and social change that accompany ageing. Changes are not only physical, but also involve changes in roles and expectations, in the way people are viewed by others, and changes amongst those other people who constitute sources of companionship, friendship and love.
- Emotional labour includes things such as: learning how to ask for and accept help; responding to changes in close relationships; dealing with a sense of declining visibility, a lack of recognition of one's strengths and experience and, in some cases, identity. The capacity to do this emotional work can be substantially enhanced by the support of others – including other older people.
- Planning and organization form a considerable part of labouring to be 'well enough'. This can involve the everyday work of planning routes to the shops to avoid hills and ensure use of services close to bus stops; or reviewing the availability of public toilets, seating and other practical supports to make the experience of going out a source of well-being rather than something that reinforces a sense of loss. It can also involve 'bigger' planning, including difficult decisions about making changes in one's life.
- Older people have to make many difficult decisions that can be experienced as emotionally and organizationally draining, rather than a source of empowerment. The way in which they are cared for and supported through these processes makes a huge difference to their well-being. The emphasis on individual choice, rather than collective attentiveness to the impact of public policies on older people's lives, and on individual attentiveness to need, is insufficient to enabling well-being.

Learning to be well with older people

- To be well enough in old age requires a supportive culture in which to grow old. Thus the learning that is required to maximise well-being is learning that we all need to do because the capacity of older people to experience well-being depends in part on the actions, attitudes and behaviours of younger people.
- This learning includes: how to give care that does not make the care receiver feel demeaned or a 'burden'; how to respond to people who may have changed in important ways because of physical frailty, memory loss, or because they are no longer able to do many of the things they used to do; learning to be sensitive to the tensions that exist between different values and to make good judgements about which should take priority in different circumstances.
- It is not only family and friends, but service providers, policy makers, urban designers and strangers who encounter older people in their daily lives who need to recognize how their actions, behaviours and decisions can enhance or undermine well-being.
- The quality of health and social care services can impact on the well-being not only of those who are actively making use of such services, but on the confidence of those concerned that they may need to in future. Whether people are prepared to ask for help when they need it may depend on the response they think they will get if they do so.
- If 'care' is considered less important than choice, if the message is that 'independence' is the most important thing to aim for, then this can undermine efforts to promote the importance of caring relationships to well-being.
- This learning can best come from maximising opportunities for people of different ages to interact personally, socially and politically, i.e. within the public spaces of everyday life, as well as the private spaces of family and friendship networks, in collaborations such as the one that generated this report, in the spaces of policy and political decision making.

Cultures, structures and resources

- Well-being is not directly related to wealth or the material circumstances of people's lives, but anxiety about having enough money can detract from well-being as well as reduce the options available to people. Older people do worry about having enough money to pay for the care they need, now or in the future. In the current economic climate fears around future financial security and cuts in health and social care budgets may exacerbate older people's anxieties.
- Understanding that well-being in old age is affected by differences that people have experienced at different stages, and sometimes throughout their lives, is important.
- Well-being in old age is not solely a function of individual choices and capacities to adapt. We need to think of how collective decisions about the way social life is organised, policies are made, particular characteristics are valued or de-valued and places are designed can all affect individual and collective well-being.
- Older people need to feel that both the physical places in which they live, and the social worlds they inhabit, are ones that recognise and include them. 'Age-friendly' communities are needed and made possible by prioritising: good public transport, accessible public buildings, and good quality health and social care services; and overcoming barriers, such as a lack of public seating, lack of public toilets, crowded streets, busy traffic, the decline of small shops / high streets, and the depersonalisation of services through increasing reliance on technology.

Whilst the losses that often accompany old age can reduce resources to be well, survival and adaptation can also generate resources not available to younger people. Well-being is not something that can be achieved solely by being active in old age, but nor is it restricted to those who are able to maintain a high level of activity. It requires action by all of us, older people and those who hope to and will become old, to create the conditions in which our success in living longer is also a success in terms of ensuring old age is a time of well and not ill being.

1. Introduction

Well-being has become an important focus for health and social policy in general, and in relation to older people in particular. *The National Framework for Older People* (DH, 2001) links well-being to ideas around active ageing. The framework sets out standards that service providers should aim to meet including:

> "Standard 8: The promotion of health and active life in older age. The health and well-being of older people is promoted through a coordinated programme of action led by the NHS with support from councils" (DH 2001:14)

Well-being has also been associated with independence. For example, the cross-government strategy *Opportunity Age* (DWP 2005) says:

> "In developing modern public services for older people, our overarching objective is to promote well-being and independence. We want to achieve a society where older people are active consumers of public services, exercising control and choice, not passive recipients"(DWP 2005: 44)

And this connection between well-being and independence was reinforced in the social care *Green Paper, Independence, Well-Being and Choice: Our vision for the future of adult social care in England* (DH 2005).

The Coalition Government has continued to argue that it is important to assess people's 'subjective well-being' in considering social and economic progress and evaluating the impact of policies and services. They are investing £2 million in a National Well-being Project which will involve the Office of National Statistics compiling a 'happiness index' by 2012.

But what is well-being? *Can* it be measured? Does it mean the same to everyone? And what produces well-being? Researchers have come up with different definitions and 'indicators' to be used in measuring well-being and these sometimes produce rather different results. Some research and policy appears to assume that well-being is a quality of individuals and can be produced through individual effort, for example the New Economics Foundation (*http://neweconomics.org/projects/five-ways-well-being*) urges people to: "connect, be active, take notice, keep learning and give" in order to maximize their well-being. Others have argued that an emphasis on the individual does not sufficiently take into account the importance of relationships between people and that, rather than measuring individual well-being, we should focus more on how to generate caring relationships that can enhance well-being.

This project was designed to develop our understanding of what well-being means to older people, and of how it is produced. As we describe in the next chapter, we quickly concluded that our aim was not to measure, but to develop insight into how older people sought to maintain a sense of well being, often in circumstances where this was difficult; what helped them do this and what got in the way of 'being well.' Similarly, our approach soon became one that understood well-being as profoundly affected by the nature and quality of different types of relationship, rather than an individual characteristic or quality. Thus, as well as looking at other work on well-being, we have also drawn on work exploring an ethic of care in order to understand what affected older people's experiences. This work starts from the recognition that human beings need others in order to survive and flourish. It identifies the universal need for care and explores the ethical as well as practical meanings of care giving and care receiving.

Thus an important aim of this project is to make a contribution to thinking about policy and practice and how this might enhance or detract from the way people experience well-being in old age. In the final chapter we offer ideas about this and we are also developing these through

ongoing work focused more directly on practice. But our findings demonstrate that it is not only those directly engaged with policy and service delivery who have a role in ensuring well-being in older age. This is an issue for all of us in the way in which we interact with older people and ageing in our everyday lives.

This project was carried out collaboratively. So we need to be clear about who 'we', the authors, are. We have listed all the members of the research team on the title page. All members of the team contributed in various ways to the process of designing the study, generating and analyzing data. We describe this process in the next chapter. This report was written by Lizzie Ward and Marian Barnes who work at the University of Brighton, and Beatrice Gahagan, who works for Age Concern, Brighton, Hove and Portslade. The contents were shared with the whole team and some amendments were made before the report was published. Thus the 'we' in the report refers to the three authors. It reflects our perspective on both the process and experience of working in a diverse team with older peer researchers, although these reflections are informed by feedback from team members. Reflection has been a key part of involvement for all team members and has been built into the project as an ongoing learning process. However, team members' reflections are not specifically referred to in this report and we plan to document these separately. We have not included lots of references to the many other studies on well-being. The purpose of this report is to capture the full range of findings from the project in order to make them publicly accessible and to provide a resource from which we, and others, can produce more targeted outputs. Other members of the team have written their thoughts on living well in later years in a booklet aimed specifically at older people.

We hope you find things of interest and use to you in this report. Do let us know what you think.

2. Co- producing knowledge: evolving a collective methodology

Where we began

This project grew out of a relationship between Age Concern and the University of Brighton. Both organisations agreed to jointly fund research which would contribute to the well-being of older people. A research fellow employed by the university worked with a senior manager at Age Concern to develop a research team of older people. Both organisations were interested in involving older people in research and in narrowing the gap between lived experience and academic knowledge. There was a shared desire to place older people's experiences at the centre of the research and work in a collaborative way.

Forming a single team with different roles and opportunities

Our approach built on a previous collaborative project: 'Cheers!? A project about older people and alcohol', which also involved older people as co-researchers. This project had involved two distinct teams of older people; four co-researchers who were actively engaged in doing the research and who were in their early 60s; and a reference group which acted as a sounding board for the research. This consisted of those who felt unable to carry out more active tasks, and who were generally rather older. This meant that we needed to manage communication and support for two groups, and ensure that they were sufficiently connected and involved.

For this current project, we decided to form a single team in which there would be opportunities to have various levels of involvement and different kinds of roles. The aim was to ensure there were no age related barriers to taking part, whilst also working with a single inclusive team.

Our recruitment process

Recruitment flyers were distributed through Age Concern's existing volunteering network. They invited older volunteers to develop research skills and bring their experience of being an older person to the project. We suggested benefits of taking part would include:

- Being part of a team of people learning together and contributing to research in an area of increasing importance.
- A chance to exchange views and opinions about what makes a difference to the well being of older people.
- A chance to develop new insights, skills and awareness.
- Having your experience and knowledge valued.
- An opportunity to engage with older people and those delivering services and to share awareness of the issues facing older people.

We recruited eleven people who were at the time aged between 60 and 87. They had a variety of backgrounds, but almost all had had some involvement with Age Concern, many of them as volunteers in various services. This meant they already had a keen interest and commitment to older people's issues, and broad knowledge and experience encompassing both professional and personal domains. However, since 'old age' covers a large spectrum of time, we anticipated that team members would bring different perspectives and experiences, all of which needed to be valued and recognised within the team as a whole. A key part of our collaborative methodology has thus been learning how to work with a group of older people at different stages of later life, as well as from different backgrounds, and trying to ensure that they were able to contribute their own particular strengths, and that their involvement was personally worthwhile and rewarding.

Beginning our collaborative working

During our initial meetings we sought to provide some context to the project and to explore thoughts and perspectives on well being amongst team members. Right from the beginning we emphasised the importance of older people as narrators of their own stories and interpreters of their own lives. By working together on the design, delivery and realisation of the research we also aimed to break down barriers between 'expert knowledge' and 'lay knowledge' - between academic expertise and community expertise. Our ability to adopt an exploratory and developmental approach was helped by the way in which the research was funded. We had considerable freedom to develop the project within the group, in response to ideas and learning emerging from the process of working together.

Defining the research questions and the methods to explore them

Our first meetings addressed the questions that defined the aims of the research:

- What does well-being mean to older people?
- What are the circumstances in which well-being is produced?
- What is distinctive about the contribution Age Concern can make to older people's well- being?
- How can Age Concern work with other agencies in the city to enhance older people's well-being?

We looked at a tool currently popular with those interested in measuring well being amongst older people: CASP 19. CASP stands for Control, Autonomy, Self-realisation and Pleasure and it attempts to capture subjective and objective factors affecting experiences of well-being. It is the kind of questionnaire that is often used to evaluate policies and initiatives that aim to improve people's lives, so is usually carried out before and after an intervention to determine how well this has worked.

Each team member tried filling in the questionnaire and we then discussed how useful it might be. The team reflected on what it was like filling it in, and agreed that it was hard to answer the questions because so many of them were affected by specific and changing contexts and this could not be reflected in tick box responses. Team members suggested that how they responded could differ on different days and, indeed, at different times during the day. There was also a feeling that it did not sufficiently reflect the way well-being is experienced in terms of relationships to others. Since our approach was concerned with capturing lived experience with all its contextual and relational aspects we decided it was not an ideal tool for us to use.

Instead we decided to use semi-structured interviews and focus groups. Open questions in the form of a topic guide would enable exploration and dialogue about what older people themselves identified as important. Our experience in Cheers! had been that this was a good way to enable older people to talk about issues from their point of view. Using a conversational style helped to put people at ease, and enabled flexibility on the part of the interviewer to develop a safe and supportive space in which to capture the person's lived experience.

Training the team and carrying out the research

We agreed a collaborative training programme that would help us think about and prepare for the tasks we would become involved in. This encompassed:

- Introduction to research.
- Ethics and research relationships.

- Firming up the research design.
- Interviewing.
- Running focus groups.
- Coding the data.

This process included development of the detailed research design; involving sharing of knowledge and skills, as well as learning about how to do research.

We evolved a four phase research design:

Phase 1: Age Concern Staff and Volunteer perspectives

This first phase sought the perspectives of those working within Age Concern on what contributes to or detracts from older people's well-being. Age Concern has been dealing with older people's issues for more than forty years, and has a mission to improve and enhance later life. We wanted to explore how those working for Age Concern try to promote older people's well-being. The values of the organisation emphasise person-centred practice and we wanted to explore how workers and volunteers sought to embody these values in their work, and what aspects of practice they thought contributed to well-being. We anticipated that such practices might be 'taken for granted' and that there would be value in making them explicit as a basis for wider learning. Interviews with Age Concern workers and volunteers used a semi-structured topic guide organised around two main themes:

What do Age Concern workers think are the main issues for older people they work with?

What is distinctive about the ways Age Concern work with older people and how might this contribute to their well being?

These interviews were carried out by the research fellow, for the sake of consistency and because we were in the early stages of the training. A total of 10 members of staff/volunteers took part from a broad range of support services.

Following the interviews feedback sessions were held at Age Concern to give an update on the research and explain the next phases. It was important to keep staff and volunteers aware of and engaged in the research, explore with them how it was relevant to their work, and explain how this first phase fitted in with the next phases and in particular, hearing what older people themselves would say. Further updates were given to Age Concern members during the course of the next phases via information bulletins and emails.

Phase 2: Age Concern service-users' perspectives on well being

The second phase involved interviews and focus groups with older people using Age Concern services. These were carried out by older members of the research team. We recruited service users via service managers who were asked to distribute recruitment flyers, using their discretion in deciding who would be appropriate. The criteria they were given were that interviewees needed to be **65 and over** and to have had contact with the service within the last 3 months. Because of the nature of the topic they were advised to exclude people currently in crisis, or recently bereaved, and people with dementia. The flyer was distributed with freepost envelopes so that those who were interested could respond to the research team with no further involvement of the manager.

A total of 15 service users (11 female and 4 male) were interviewed by 5 of members of the research team. Interviews varied in length owing the different conversational style of participants, but generally lasted between 1½ to 2 hours. Most participants were interviewed in their own

homes unless it was more convenient for them to be interviewed at Age Concern premises.

A consent process was reiterated at the start of each interview (having already been explained in written form prior to the interview). Consent had to include a caveat relating to adult protection and safeguarding procedures in keeping with Age Concern's duty of care and mandatory role in multi-agency guidelines.

Interviews were recorded using digital recorders so there was no need to take notes, although some basic details about age and personal circumstances were recorded manually at the end. Each participant was offered a choice of shop voucher to the value of £10 as a gesture of thanks for taking part.

Research team members were encouraged to write notes and reflections after the interview and to make contact with either the research fellow or senior manager with any thoughts, observations or concerns.

A breakdown of the participants' age and gender is shown in Table 1 below. Other biographical details in relation to the social and physical circumstances of those taking part, including disability, ethnicity, retirement status, general financial situation, and any caring responsibilities appears in the Appendix

Table 1 Age and gender of phase 2 interviewees

Age	Male	Female	total
65 – 69	-	1	1
70 – 74	-	1	1
75 – 79	-	2	2
80 – 84	1	2	3
85 – 89	2	4	6
90 – 94	-	-	-
95 - 100	1	1	2
Total	4	11	15

In addition to one to one interviews, two focus groups were carried out with 12 older people using Age Concern group activities. These were conducted by four members of the team. Flyers were left with the activity group inviting members to take part. The focus groups were held at the end of the activity group's regular meeting and a light lunch was offered to those taking part. Each focus group lasted about one hour and included a shorter version of the interview topic guide designed to elicit more general group responses to and reflections on the issues. (Details of the focus groups are included in the appendix).

Phase 3: Perspectives of other older people in Brighton and Hove

In the third phase we explored the experiences and ideas of people over 65 living in Brighton and Hove who were not Age Concern service users. Once again recruitment flyers were used to attract participants to take part in individual interviews or focus groups. These were distributed through local older people's networks, in sheltered housing schemes, day centres and community groups. Our aim was to include a wide range of people in different circumstances, whilst recognising that it was not possible to ensure a representative sample.

Fifteen individual interviews were conducted with 9 women and 6 men. Table 2 below shows the age and gender of participants, some of whom were virtually housebound and others who were very active (for more details see Appendix).

Table 2 Age and gender of phase 3 interviewees

Age	Male	Female	total
65 – 69	-	2	2
70 – 74	2	1	3
75 – 79	1	2	3
80 – 84	-	1	1
85 – 89	2	1	3
90 – 94	1	1	2
95 - 100	-	1	1
Total	6	9	15

Of the phase 2 and 3 interview participants, 40% were aged between 65 and 79, 43% were in their 80s and 17% in their nineties. In terms of cultural differences, the majority of the interviewees defined themselves as White British/ English /Welsh/ Scottish, and one as Afro-Caribbean. Thus we have a good spread of people in terms of age and gender, but only limited interview data from black and minority ethnic older people.

In addition to one to one interviews, five focus groups were carried out involving 47 older people. Three focus groups were held with people who belonged to special interest social groups; one was held with members of an older Black and minority ethnic (BME) women's group, and one was held with a group of residents in a care home. All those who took part already knew each other and mostly the focus groups were held after their regular meeting. As in phase two, these focus groups were conducted by four members of the team using a shorter version of the interview topic guide designed to elicit more general group responses to and reflections. We contacted a number of groups with information and flyers with to capture diverse experiences across different geographical areas and living circumstances, as well ethnic and cultural differences. (Details of the focus groups are included in the appendix).

Making sense of what older people told us

We tackled the next stage in the research process – making sense of what older people had told us in the interviews and focus groups - collaboratively as a team with members again taking on different roles within the process. This was a long process undertaken over a period of 14 months comprising three stages:

Coding - closely reading written transcripts of the interviews and organising sections of the transcripts under descriptive categories as the first stage of identifying themes and patterns in the data. This involved:

- training team members on coding
- producing a coding framework and guidance for coding
- working out a process for co-coding including discussions of coded materials

Thematic analysis - the coded data was organised into thematic sections and brought to team discussions for reflection and interpretation. This involved:

- collating the coded material into thematic sections
- team members summarising thematic sections and presenting to the rest of the team for discussion

Writing up

- gathering those discussions into written form
- using this to structure findings in the report

The presence of the team's experience, particularly in the thematic analysis, was really important. They reflected on the data from their own lived experience and this enabled a richer understanding of the meaning and significance of what was said by interviewees. Following the detailed analysis of the interviews we reviewed recordings of the focus groups to check for any additional perspectives but these were not transcribed hence the limited use of quotes from the focus groups.

Phase 4: Knowledge exchange with policy and practice

One of the aims of the project was to understand how Age Concern can work with other agencies to enhance older people's well-being. The fourth phase of the project was designed to address that aim and begin a process of engagement with practitioners and other service providers. When we set out we envisaged the exchange of knowledge and skills as an interactive process, involving developing tools and resources relevant and useful to those working with and providing services for older people, as well as creating links to the wider strategic and policy agenda. As the research was drawing to a close we were successful in securing funding from the Economic and Social Research Council (ESRC) under a scheme that aims to apply research findings to have an impact on policy and practice. As we write this report are starting to plan a process of applying findings to practice by working with practitioners in the statutory and voluntary sectors.

Our expectations

Although from the outset we were clear about our commitment to a genuinely participative project, we also recognised the different roles and responsibilities of university researchers and the Age Concern manager. We also recognised that we all had much to learn about working in a team of people with a wide age range as well as different backgrounds and experiences. There were instances when specific expertise and knowledge clearly needed to guide how we worked (for example, in relation to the need to abide by research ethics and governance procedures). But we endeavoured to make each stage of the research process a collaborative one in which everyone felt involved and included.

This resulted in frustration for some team members who wanted clearer direction, and there were some doubts about whether we would get anywhere. Team members sometimes voiced anxiety about where the project was going: was it unfocussed?; what would be the outcome?; and how would we make sense of all the individual interviews and focus groups and turn them into something that could be used to effect positive change? We ourselves had to learn more about when to take the lead and when to ensure direction was shaped collaboratively, when to give reassurance and certainty about the benefits of undertaking such a project, and how to acknowledge the uncertain aspects of the research without this becoming demoralising. We were aware of the tension between our responsibilities for completing a time limited research project and our desire to offer learning opportunities to those with little or no previous research experience. This tension was always present, and we recognised that at different stages of the research different team members found the experience both frustrating and stimulating. Towards the end of the project we explored these experiences directly with those who took part.

Our existing knowledge about insider research meant we also recognised that involving older people in research about other older people would bring them face to face with issues which may be directly relevant to and current in their own personal lives. Although many had already worked as volunteers and so had already confronted some of the challenges of ageing in a helping

capacity, this could be more difficult in a research role where they would not be resolving problems or offering direct support to the people they interviewed.

So as the project progressed we needed to be aware of the potential impact of listening to other older people's accounts of their lives on team members. We needed to be sensitive to their feelings and responses, noticing and being aware of significant personal life events such as bereavements, health difficulties, or difficult questions about the future. One member of the team decided to stop being involved because she found some of the accounts too upsetting. Offering support was an ethical commitment that was necessary to embody the values underpinning our methodological approach. This required extra time and became even more important during data analysis.

As we write this report seven out of the original eleven members of the team are still involved. Apart from the woman who found it upsetting, one left because he moved and two others had decided that they wanted to spend their time on other things. Both these had experienced some frustration with the pace of participative work. However, for the others, the experience continued to offer important satisfactions and as this stage of the work drew to an end, there was a strong feeling that both the project and their involvement had been worthwhile. All those who had left were amongst the youngest members of the group.

A methodology based on ethic of care principles and person centred practice

Our approach to ethics was embedded not only in formal research ethics, but also in an ethic of care (see Discussion section) and in Age Concern's person centred practice value base.

Person centred practice for Age Concern means:

- Respecting each older person as a unique individual
- Providing a warm and caring atmosphere
- Giving each person time to explain what they want/need
- Listening non judgementally
- Helping improve life through the quality of our interactions - even when we can't resolve the person's problem
- Allowing and encouraging people to express their views and feelings
- Supporting people to make their own choices/never imposing views or decisions on people
- Recognising the complex contextual and relational aspects of being
- Recognising the importance for people of continuity - even if this means them doing things which now place them at greater risk

We also worked with ideas deriving from care ethics to develop our approach to ethical relationships within the research team, as well as in our relationships to the older people who took part as interviewees or participants in focus groups. We discuss these ideas as they relate to our findings and learning from this research in a later chapter.

Involving our team of older people in research was thus not just a matter of including them in a set of activities, but was also about the nature of the relationships we developed during the process and how these were connected to our subject matter, our developing understanding of well-being and ethical research practice. It involved being attentive not only to the different contributions that different team members felt comfortable with making, and to the practical support necessary to

enable them to work with us, but how we could ensure and possibly promote well-being through the ways in which we worked together. This involved time for social contact and one to one support, as well as for getting the tasks of the research carried out. It involved recognising and where possible responding to the different experiences of individual members of the team, and being aware of other things happening in their lives that affected their work on this project. We don't think we always got this right, but hope that for most of the team the experience was one that contributed more than it detracted from their well-being.

The process of producing knowledge together

Participatory research is also about working together to generate new knowledge that would not be possible if either 'professional' researchers worked alone, or older people with no previous experience of research worked without the input of 'academics'. We think that using qualitative rather than quantitative research methods is more likely to enable this to happen.

A lot of research, including research about well-being, is carried out by asking large numbers of people standardised questions. Attention is paid to people's characteristics, for example, their age, gender, class and cultural background, to assess how this group of people who were asked the questions – the sample - might or might not be representative of a larger group of people or the general population. The answers from the sample are analysed through processes of quantification – adding together categories, comparing different variables, such as the number of men or women who answered a question in the same way – and the results tested numerically to assess the statistical significance of the answers. Researchers can then make generalisations – statements about trends that can be predicted from the results of numerical tests. For example, if 900 men out of a sample size of 1000 who were representative of all the men who live in the same place (X) answered a question in the same way (Y), it would enable the researcher to make a general statement that those men who live in X think Y. This type of research is used to provide evidence to support or discount a particular idea or theory. What counts as evidence will be shaped by: the precise questions asked – both the selection and phrasing of these; the way in which responses are defined (typically a number of options are set out from which people have to select); the ways in which the answers are analysed; and what is then said about the analysis. Weight is given to the 'scientific' processes involved, for example 'objectivity' - if the processes were repeated by other researchers would the same results be produced? Whilst older people could take part in defining the questions and administering the questionnaires, the older people completing them are not able to introduce other topics that they want to talk about and cannot add comments about the reasons for the answers they give, or what this means to them.

The qualitative approach that we adopted was much more open in enabling older people to shape the content of interviews and focus groups. As well as involving older people in the team carrying out the research, interviewees and focus group participants were able to shape what they talked about; to reflect on issues that the team themselves might not have identified as likely to be important; and to discuss why things were important to them and what precisely it was about issues (such as where they lived), that made a difference in terms of their well-being.

In team meetings we were able to reflect together not only on what was said in interviews, but how people spoke about things: did certain issues upset them, for example. We were able to discuss what sense we could make of this and to reflect on our own response to what was being said. Part of this process involved the older team members debating how to make sense of what interviewees had said by drawing on their own experiences and those of other older people. They did not always agree with each other. But the discussions that took place provided further insight into the processes associated with subjective experiences of being well (or not), and emphasised the importance of understanding such experiences in the context of both objective circumstances (such as health status), and more subjective issues such as the priority accorded to different values such as privacy and security.

This type of research does not lead to an aggregation of answers or concise set of generalisations: what proportion of older people say the physical environment in which they live is important to their well-being, for example. Rather it helps us understand how different aspects of people's lives affect their experience of well-being, and how older people seek to shape their lives in ways that can enhance well-being and what resources they draw on to do so.

By looking at the stories older people tell us, we can broaden awareness of the kinds of issues, themes and dilemmas faced by people living in different situations and whose life experiences are different. We can also increase our understanding of the factors that detract from well-being as well as contribute to it. This understanding can help suggest what action is necessary to ensure more people can be well in their old age.

3. Thematic Findings from Phase 1: Age Concern staff and volunteer perspectives

Interviews with Age Concern staff and volunteers were designed to explore what they understand to be the main issues for service users, and how they think Age Concern contributes to older peoples' well-being through the services it provides and its culture of practice.

People access Age Concern services for help with issues ranging from advice and information on matters such as housing, pensions, and benefits, to practical support to meet emotional and physical needs such as nail-cutting, counselling and home care. Age Concern also provides services relating to fitness and health, socializing and volunteering.

Different needs and issues facing older people

Interviewees highlighted the different needs and issues of those at the younger and older ends of the age range. They thought some differences are generational in terms of expectations and cultural beliefs; others relate more to ageing and the physical and emotional changes that ageing brings. Age-related differences sometimes relate to the level of care needed, for example those over 80 tend to need higher levels of care. Staff observed that within the older group there can be a loss of confidence, lower expectations and a feeling of not wanting to be a burden. In contrast those aged 50 – 70 are generally more active, want to be involved in their communities, and have higher expectations around being engaged, participating in activities and being independent.

One of the main issues that staff felt affected the older, more vulnerable service users was isolation and loneliness. This was particularly apparent in those accessing care and rehabilitation services where clients have lost mobility and/or confidence to go out and lack social contact as a result. Bereavement and the gradual loss of friends and family can result in an increasing sense of isolation and feeling cut off from the world. Staff felt that for those people who are unable to get out, having regular social contact makes a big difference to well-being:

> If you can just spend a bit of time with someone who otherwise doesn't get to see anyone … you can really raise someone's well-being by just engaging with them and making them realise that they are not isolated and they are not alone and there are people thinking about them. [staff interview 4]

Staff suggested that technology and the internet could play a positive role here. Some people already make use of webcams and email to keep in contact with family and staff. Staff commented that development of Nintendo Wii within sheltered housing was a good example of using new technology as a way of increasing social contact.

Interviewees felt that people in the oldest age group may not know what services and help are available, whilst those at the younger end of the age range generally have more awareness of services. Some people find it difficult to acknowledge their needs for support and are reluctant to ask for help. Staff reflected that often this is linked to a sense of pride and/ or embarrassment:

> You know, they don't want to be seen as the 'weak one' or the 'one who's struggling because she's getting old'. [staff interview 2]

Recent changes in adult social care, such as the introduction of individual budgets and the self-directed care and personalisation agenda, were discussed in relation to Age Concern service users. At the time few older people were receiving individual budgets. Generally interviewees felt that offering older people choice could in principle be empowering, but it might not be suitable in all cases. Reflecting on the experiences of those who already have direct payments, one member of staff commented:

> It works well if the client can look after budget on their own but if things change and they can do very quickly then it becomes an issue … can actually lead to more trouble than it's worth. [staff interview 10]

In general, staff felt there is more awareness of the issues older people face because the population is ageing. However, many felt older people continue to face discrimination and the impact of ageism. Staff stressed the importance of intergenerational contact to counter negative stereotypes of both older and younger generations. They had seen positive benefits of such interactions through Age Concern work.

Interviewees commented on the positive aspects of services and activities developed for the 50 – 70 age range, and the importance of preventative work. However they felt that more vulnerable and frail older people should also remain a key focus for services and identified a gap in service provision around befriending:

> For older people who are mobile and are mentally in good health there's a lot out there but for the people that aren't there is very little … a huge gap … where people are completely on their own at home for days on end … they are the most needy and there's not much (people want to do about it) because it's not fashionable. [staff interview 10]

Interviews covered aspects of Age Concern's services and practice and interviewees were asked to reflect on how these may contribute to older people's well-being. Although differences between age cohorts were identified, the approach to working with clients is the same across all age groups. A number of themes emerged which together form a distinctive 'culture of practice' that Age Concern seeks to promote.

Person-centred practice

The importance of listening and responding to what people say was emphasised. Interviewees recognised the importance of allowing people to make their own decisions about the services they receive. This approach was described as potentially empowering for the person, particularly for people who have lost some of their independence. It was also considered more effective than imposing solutions not based on the person's own wishes:

> It's allowing them their time and their choice to be able to say to say yes or no really … it's about adjusting the way you are to every individual how you are with them … it's about building up trust … and allowing them to make their own decisions and allowing them to tell you what they want to tell you and working on that…. because we haven't pushed them they will come back …rather than saying you have got to have this … if you force someone to have something they don't want they are going to want it even less. We can say to the clients 'it's all about you … we've got this, this and this have a think about it … you don't have to have any of these services it's up to you'. [staff interview 10]

Implicit in this approach is an awareness and understanding of the issues associated with ageing. Staff recognise that difficulties in accepting help are connected to the older person's desire to retain their sense of identity and to feel like a whole person. Interviewees stressed the importance of allowing people time to come to terms with their situation and accept the need for help. Letting people make decisions is crucial, as imposing services could negatively contribute to their sense of loss of independence and be counter-productive in terms of well-being.

It is not always possible to do what older people want, but interviewees highlighted the importance of 'being present' with the person and acknowledging their situation and feelings, rather than dismissing them. Accepting limitations of what is possible to achieve can help staff to be attentive to small things that might make a difference to the person's well-being and to respond accordingly.

All the staff and volunteers thought this approach was what distinguished Age Concern from other service providers and was part of the core value base of the organisation:

> The way Age Concern works is that we care more, we listen more and we treat people like individuals. [staff interview 3]

Time

Time was identified as an important factor in being able to work in a person-centred way. This included having sufficient time to spend with each person and to talk through issues. Staff noticed that often there are other issues than the immediate one presented. By giving the person time and opportunity to talk, and having patience and listening carefully, it is possible to gain a more accurate picture. There is awareness that the complexity of the issues older people face requires flexibility and being able to 'look outside the box'.

Interviewees recognised that time was also important within the organisation and part of their practice and professional development involved support and learning from colleagues. Having enough time 'to do the work properly' was viewed by staff as something that contributed to their job satisfaction. Many interviewees had also worked in the statutory and private sectors where there were constraints on the amount of time allocated to each service user, which they had found frustrating and stressful. One member of staff who had previously nursed older people in the health service commented that when she worked on a hospital ward:

> There just isn't that relationship with older people because there just isn't the time, the staffing or the opportunity. [staff interview 5]

Relationships

Building relationships was identified as fundamental to person-centred practice. Interviewees felt that the quality of relationships can impact on the intervention. As well as listening and responding to what the older person wants, building trust, being consistent and reliable were also considered crucial. As noted above, internal relationships across the services, working holistically and supporting each other were also considered important aspects of the work environment and interviewees commented that there is a sense of 'pulling together and being a team'. This in turn impacts on service delivery and people felt able to do their jobs well because internal relationships are supportive of the approach and so can shape the way older people experience services.

Personal experiences and motivations

In understanding what staff and volunteers enjoy about working with older people it became clear that all had in some way been touched by personal experiences with older people, such as caring for parents or relatives. They draw on their own understandings and experiences of the ageing process and knowledge that life can be difficult for some older people. Many recounted examples of an older person being badly treated and so had a strong awareness of the psychological impact of age discrimination from personal experience. A strong commitment to social justice emerged in many accounts and this was clearly a motivating factor in working for Age Concern and with older people. In response to a question about the personal qualities and attributes staff and volunteers bring to Age Concern, a commitment to 'caring' and respect for older people were identified as the common features within the organisation. Many spoke about feeling a sense of debt to the older generation, particularly for those who had lived through the war. Many were interested in hearing about older people's lives and learning from their experiences over a lifetime. They felt that this is important for the passing on of personal histories, and for a sense of continuity between the generations.

Staff acknowledged that working with older people can be personally challenging, particularly working with vulnerable older people who are not in good situations or working with people who are facing their own mortality. In spite of this staff commented that their work was also very rewarding:

> I feel very privileged to be working for this service and having seen the way that it does really reach out to people who, at times, have nobody else, and nobody to really listen to them. [staff interview 4]

4. Older people's perspectives: Thematic Findings from Phases 2 and 3

As we outlined in section 3, our approach has been to place older people's experiences at the centre. Our team of co-researchers' own understanding and experiences played a significant part in shaping the research design and carrying out the research. This was also the case in relation to analysing and interpreting the data.

We started the interviews and the focus groups with an acknowledgement that well-being is not easy to define and will mean different things to different people. We explained that the purpose of interviews was to explore the topic of well-being to understand what contributes to, or detracts from, well-being in later life. Co-researchers used the topic guide to help structure the interview and respond to what interviewees talked about. A similar approach was adopted in focus groups where participants were invited to explore and discuss what they felt was important to well-being.

Through the process of analysing and interpreting what people told us, it became clear that well-being comprises many different factors. A number of interconnected themes appear and reappear in people's accounts of well-being. These include relationships; communication and connectedness; change and transitions; continuity and adaption; security; self and identity; autonomy and control; age and diversity. Individually and in combination these impact on the way people feel about their well-being in diverse circumstances.

These themes not only cut across different areas of people's lives, they also interact with each other so that isolating individual factors in relation to a person's well-being is not straightforward. To make sense of what people told us we have organised the findings in the following four sections: **people; health, care and support; resources; places and environment.** Many of the interconnected themes appear in each section. This enables us to build a picture of the ways in which well-being can be understood as a dynamic process, something that is created between and through people and their relationships to others and the social worlds we inhabit, rather than something than can be understood as an individual quality. There were some things that virtually every person talked about and some things that very few people talked about. Rarely, if ever, was there one single factor that in itself determined a person's well-being. Rather it was the interactions between subjective factors, interwoven with personal and individual biographies, as well as more objective factors related to material circumstances and resources, that contribute to well-being[1].

4.1 People

In this section we draw together themes that relate to the ways in which people featured in participants' accounts. These included family members – spouses, sons and daughters, siblings; friends and neighbours; as well as casual acquaintances and 'strangers' encountered during everyday interactions. In this section we explore what participants said about the ways in which 'people' are important in relation to well-being.

Relationships

Relationships of all kinds emerged as significant in many different contexts and feature in one way or another in each of the section headings. Here we include the ways in which people talked about relationships within families, friendships and with neighbours, as well as casual interactions with people in everyday encounters (which we have called 'stranger relationships'). All of these different types of relationships highlighted not only the importance of social contact of some kind in most people's lives, but how the nature and quality of the interactions we have with those around us can have a big impact on well-being.

1 We have changed the names of all the interviewees whose words appear in the quotes

Families

The interviews revealed diversity within family relationships, but some common features emerged about the way relationships change over time. As people get older, issues such as the amount and frequency of contact; the need for support and care; and the provision of support and care for other family members, are increasingly important. For some, families were a source of support and security as well as joy and pleasure. For others family involved difficult and painful relationships, distance and estrangement, which may have been part of a lifetime pattern or have arisen as they got older.

For those who were parents, their relationships with sons and daughters were often central to the discussions. Many expressed a desire to see them more frequently, especially if children did not live locally, and in some cases children living far away was a source of sadness. Many identified having good relationships with their children as an important contributor to their sense of well being:

> Yes, very important, I'm happy to say that we're a pretty close family and my children, they're all very fond of each other and we're all very fond of them and they're very fond of us and it's great… It's fairly unusual, I mean living amongst my friends, I can't think of many who enjoy the same sort of relationship, you very often find that children are, when they grow up they grow apart and don't want to know each other. [George, 86, married, own home with wife]

For some family relationships took on more significance with age:

> ...my sons, I've only got two boys, I haven't got anybody else. So, yes, I do value them, they are very good to me, both of them, in different ways, but they are very good to me. And I haven't got anyone else very much.... [Margaret, 83, divorced, sheltered housing on own]

> I suppose the highlight in our week is when my daughter and son-in-law come ... and grandson from time to time, not often but from time ... to time visit us and this is very exciting because in a matter of weeks now his wife will have her first baby which will make us great grandparents so that is a moral boost, you know, we have reached that stage*. ...* We phone several times a week and that kind of thing and we know they are always there if we should want them, and they are the most important relationship because we don't have any other relationships. They are casual. We haven't any friends in this block.[Jacob, 96, married, own home with wife]

Not all the interviewees had good relationships with their children. Some spoke of estrangement and having little or no communication with sons and daughters. They reflected on the continuing impact this has, not only in terms of a lack of practical support, but emotionally causing pain and unhappiness:

> She doesn't want to know now. Cos I phoned and I heard the phone go down....now I have come to being on my own.... [Eddie, 85, married, council rented on own]

> if I'm sick here now I haven't got anyone anywhere that I can phone to say, 'come over and spend a weekend with me because I have a stroke and I'm unable to help myself', there isn't anyone. My relatives I have in London, they have the children and they can only maybe spend a day [Reggie, 90, divorced, sheltered housing on own]

> ... inwardly, my heart's breaking but I mean I've cried all the tears but then I sit down and I think 'pull yourself together Grace, there's nothing you can do about it. Just take it as

> it comes. If they come, welcome them' ... But when I shall see them again I haven't the faintest idea. When I see them they normally pop up on my birthday, and Christmas Day. The children don't know me – the great grandchildren – they look at me as if I've come from another planet, you know. [Grace, 97, widowed, own home on own]

Others had more positive intergenerational relationships and described the joy of spending time with grandchildren and valued having contact with a younger generation.

> I love playing games with the children ... I've got a lot of toys here. I went out and bought a lot of toys like puzzles, snap and ludo and snakes and ladders, all these games so that when they come to me I play the games that maybe mummy and daddy don't have the time to play. [Sally, 67, widowed, own home on own]

> I very much treasure my granddaughters ... because they do keep in touch. Either e-mails ...on the Skype too. But, I do appreciate the fact that the eldest one, well she phones up often, doesn't she, and are great because I always say they keep me modern [Agnes, 86, married, own home with husband]

There was recognition that maintaining satisfactory relationships requires diplomacy and careful handling. Many described a process of learning to relate to their adult children in different ways. This was evident in the ways people spoke about how they interacted with their adult children and the changing nature in their role as 'parent':

> ... having a large family the children don't feel that I'm on top of them I suppose because I've got to spread myself out. ... I don't interfere in their lives so I try to be supportive but I don't tell them what to do, what not to do, I might not agree with a lot of the things they might do but I keep my mouth closed. [Sally, 67, widowed, own home on own]

> she was very wary of me interfering. I mean, I just once said to my son, not…I wouldn't have dreamt of saying anything to her…I think the bath water's a bit hot, you know because the temperature was like 30 or something, and she's never forgiven me for it. [Rachel, 74, married, own home with husband]

This negotiation was often coupled with a reluctance to be 'a burden' on children. Accepting help from adult children, as well as recognising the role reversal between parents and children as a factor in getting older, appeared to be one of the biggest shifts older parents can face.

> I never demand of them that they come and see me if they're busy or they've got things on. I want them to live their life because I've had my life and a good life and I want them to have a lovely family life as well. My expectations of them wouldn't be that they should have to burden themselves with me, I think it's different when it's your partner, when it was your husband ... that was ill, and I think that's completely different. But I think to expect your children to do it I think it's very hard. [Sally, 67, widowed, own home on own]

As we will see in the section on **Health, Care and Support** the issue of role reversal was a recurring theme, not only in relationships with children, but also between husbands and wives. In changed circumstances where the need for care arose, the accompanying change in the relationship dynamic often held implications for identity and maintaining a sense of self. For instance, someone whose identity had been linked to being a mother or wife can find it hard to accept care from those she has looked after.

Friends

As well as relationships with family, most people spoke about the importance of friendships.

Not all of those interviewed had a family network and friendships and social networks played an important role in the absence of kin. Just as family relationships change as we get older, there was also recognition that friends and the meaning of friendship change as we age. Ageing, ill-health and physical distance may make it harder to sustain friendships and the loss of long term friends, with whom we have shared experiences, either by death, distance or infirmity, was felt very strongly. The loss of a shared history as well actual companionship affected many who reflected on the difficulty of forging new relationships.

> I think I've always got a lot out of, I suppose, personal relationships...particularly friendships because I have no brothers or sisters you see, and I miss them, ...miss having close friends in my peer group....I meet all these different people and some you take to and some you don't and that's life isn't it, but it's ....not so deep in a way, is it, it's a superficial sort of thing [Margaret, 83, divorced, sheltered housing on own]

> but I have now lost seven people since I moved which is quite extraordinary. People that were meaningful friends. Very, very sad and you can't replace them quickly you know. It's just. So I feel that gap enormously [Kathleen, 67, single, own home on own]

Although making new friends following loss and bereavement can be hard, it was nevertheless considered important by some people:

> It has always been important. No, the change has been being a widow, not having an immediate partner that has made external relationships more important [Joan, 74, widowed, own home on own]

But practical issues of forming new friendships were talked about and some people commented that finding others with common or shared interests was not always easy or necessarily a straightforward solution to bridging the gap left through bereavement.

> But I do desperately need, and there's no point in saying, oh, join an evening class or join this and that because people are not, I don't actually think they're actually joining things with the objective of making any sort of firm friendships. I mean, I get this at the poetry group, you go in and the recitals are over and everybody is up and away, you know, quickly, they don't hang around to pass the time of day or anything else. [Pam, 79, widowed, sheltered housing on own]

> I find it difficult to form new relationships … we all lose our friends and when we get older it's a closed book … people are kind and talk to you but you cannot form a close relationship. [Focus group 5]

> I lost my best friend … a very good friend and since she's gone I can't replace someone like her … I have lots of acquaintances but acquaintances are not friendships. [Focus group 5]

Neighbours

Relationships with neighbours can also be important. Good neighbours can play a vital role in emotional security and support:

> No, not a lot of friends, no....But my neighbours are extremely good....they are almost like family.....but I know every day that unless they see my bedroom window open, [names] are in like shot. So I am not worried about being alone. But I think if one didn't have that, you could be nervous (Connie, 87, widowed, own home on own)

For those fortunate in having good relationships with their neighbours, regular contact with them provided a major form of social contact, especially if getting out of the house was difficult.

> So, if somebody breaks up the day, that's good, or [name] next door when she is always out each day, she might call through the window, alright [name], you alright? Want to come in for a cup of tea? If I'm not doing anything I say yes and quickly go in or if she is on her balcony, she loves the sun, we talk to each other. [Elsie, 81, widowed, own home on own]

However, many felt that with the passing of time neighbourhoods can change and you no longer know your neighbours. A move to a new area or housing situation meant that some did not know their neighbours. Although reasons for this varied, some thought that people were less friendly or less inclined to get involved with neighbours now than in the past.

> Then in the middle flat they're a couple…I truly can't remember speaking to them, I see them go out in the car but to actually have a conversation…I can't tell you when. Then there's the other flat in the other corner, that's empty, that's waiting to be let, again the person's bought it and is going to let it. I hate these letting flats…when we moved here there wasn't one letting flat, they were all residents.
> [Grace, 97, widowed, own home on own]

> It's not a place to get to know anybody….I've got someone with flat, a door absolutely opposite me, I know there's somebody there because I saw the furniture go in, and I saw the decoration with the doors wide open while they re-did it, and I've never seen or heard them go in or out and, presumably, they've never seen or heard me, and our doors are bang opposite like you and me, and that's really what it's like. … you might meet somebody down in the laundry room or the ground floor..... but we don't know one another, just passing acquaintances really. So I wouldn't say you make many friends here [Margaret, 83, divorced, sheltered housing on own]

Strangers

Everyday interactions with others, who may not be known personally, can be important. Conversations struck up in shops, on buses or waiting for buses contribute to a sense of being connected with others and the outside world.

> because I like the human contact you know, the same as I never use the, down in the supermarket, I never go to this place where you book yourself in I go through the check out cos you can have a bit of banter with the checkout people and there are certain checkout people I have, I have struck up a relationship with down there, so that's good [Charles, 79, widowed, own home on own]

> …People will often talk to me actually. It's strange. People will…I otherwise will chat to people if they look down and out and sorrowful at the bus stop where I'm waiting. I tend to open up the conversation [Kathleen, 67, single, own home on own]

> When I go out I talk to people … and if you say nonsensical things …it sparks something off … it's bit like performing and if you go out and talk to people and perform a bit then you feel good… make them laugh. [Focus group 4]

Other relationships – pets and animals

This section has focused on different relationships with people and has highlighted the importance of social contact in most people's lives. Another type of relationship, not strictly speaking with

'people' was present in some older people's stories and these related to pets and animals. Pets, most usually cats and dogs, were described in terms of the companionship they offer and as 'family members' in relation to aspects of care giving and care receiving (which we discuss in more fully in the next section). Joan, who had cared for her husband, reflected on caring and having cats:

> I mean caring for my husband the last, well five or six years it has been quite important, and I do find that a sort of gap and then I had cats, and the last one of those has just died and that was a need, and for the last year I was looking after the cat as well. And I miss that. Yes, I miss not having somebody to care for, yeah. [Joan, 74, widowed, own home on own]

Pets also connected to social activities and social contact, for example taking a dog for a walk provides exercise and an opportunity to meet other dog owners in the park. For some, particularly following the loss of other loved ones pets were a source of comfort. One focus group participant who was widowed spoke about her dog in relation to loneliness:

> I've got a dog I wouldn't be without him [Focus group 4]

For pet owners the relationships were clearly important and impacted on decisions about where to live. For one dog owner, moving into sheltered housing was made easier because his dog would be able to live there and seemed happy to be going there:

> its always him [the dog], he decides he wants to go for a long walk, and its odd but we always go as far as [the sheltered housing scheme], and he pauses at the garden round the back and looks in, and once the manager saw us and she said 'Oh how are you?' and this sort of thing, 'Is this the dog?' I said 'Yes', and he just sat there. [Simon, 73, single, sheltered housing on own]

Change and transitions

As we have already seen, many people commented on the changing nature of families and the communities in which they live – of children and grandchildren living in distant parts of the world; of children having moved away from home for university or relocating because of work; or indeed of having moved themselves to their current home post-retirement. It was clear that negotiating change and loss of friends and significant relationships was a feature of many people's lives as they grew older. This was often experienced as a loss of connection to a shared past, and in part, a loss of continuity with a person's sense of themselves and their identity. How people negotiate these changes varied and depended on individual personality as well as factors such as having a health condition or caring responsibilities:

> of course I do like company and I have to say that I am very lonely at times having lost all these very good friends you know, and you don't establish, I mean you are friendly with a lot of people, I am a very friendly person actually you know, I am actually friendly, I reach out to people but that's different from friendship and friendships as you will know too are things that you establish over a period of time aren't they? And if you are restricted somewhat because of health issues or what have you, it puts the brake on even more doesn't it.[Kathleen, 67, single, own home on own]

> Yeah we had more friends. And people find [husband]'s condition disturbing I think. I, to an extent I can understand it because it's unpredictable, in many people, not [husband], but in many people it is unpredictable and I have spoken to other carers who find the same thing. [Jennifer, 76, married, own home with husband]

Others noted that as their children became adults the dynamics within the relationships changed and this entailed a kind of role reversal:

> Well I think once they all leave home, there's a change in so far that you're no longer the… when they're young, you're like the middle of the wheel and they all come to you about everything and once they grow and go away, although we're still in close contact, you are no longer the person who's sort of in charge, coping. [Ruby, 84, married, own home with husband]

> They [her children] listen to you and everything…and the children are very, very good but they don't value you, I found that when my husband died, or when he became ill, that they valued us as a couple and they listened to us ... but me on my own ... [Sally, 67, widowed, own home on own]

For many, losing a spouse marked the most significant change that had to be faced. For others, particularly those in the 80s and 90s, the loss might be compounded by having outlived many friends and family members.

> a lovely husband, I mean he was the one and only, which is unusual today ... we would have been married 60 years but he died just before our 60th anniversary.... it was difficult. But, I mean, I had to cope. I was here on my own, I was left. So that's it. .... It's the friends that I've lost that have been so close and they've all died and I haven't got anybody left. [Grace, 97, widowed, own home on own]

> Of course, it's, people are, a lot of people of our age have to spend a lot of time on their health but, of course, the biggest change is that they die. I've stayed friendly with a group from school, my girls' school, there were seven of us and there are four of us left. [Rachel, 74, married, own home with husband]

But for some a bereavement had opened up unexpected possibilities of developing new friendships or activities, of overcoming and surviving the loss.

> So he is my oldest friend ... who was 90 yesterday. I'm the only person now that knew [place] when he was a boy... so I've known him since he was nine and he's known me since I was two ... and his wife died this year and he's absolutely devastated. He's never been on his own in his life ... so we talk alternate days probably and we have talked more in the last couple of months than we have in our whole lifetime. But because we've got shared experiences we're talking about people we both know and we could never have done that when [his wife] was alive actually, although she was a very good friend of mine, because I think she would have been jealous. [Margaret, 83, divorced, sheltered housing on own]

> I mean my wife she loved musicals ... if we ever went up to London it was to a musical. Now I don't have to do that. She didn't like straight plays. So think what she was missing. But still, there we are so, things are different. I can do what I like now which I always used to, you know, go along with what she wanted to do. [Charles, 79, widowed, own home on own]

One of the ways in which people talked about meeting the challenges and coping with changes in life situations was by retaining a sense of connection to others.

> ... with getting older and disabilities come up, you know, with different problems, I have arthritis at the moment... its... [keeping up] connections, like that the telephone is always up to date, and keep in touch, if they have got them, family, friends, call on them ... so it

is keeping in touch, and doing something, have somebody call in say, if not twice a week, once a week at least. Sit and have a chat, talk, play cards or just sit and watch television, have a cup of tea, not to sit on your own .... I think you should have some connection with the outside world as often as you can possibly can, if you are housebound [Elsie, 81, widowed, own home on own]

4.2 Health, Care and Support

In this section we draw together themes that relate to participants' experiences and perceptions of the significance of **health, care and support** in relation to well-being. People talked about their own health and about learning to deal with their own illness and disability, or that of spouses and other family members. They also talked about experiences of care and support services that help with daily living. People talked about professional health and care services provided by different sectors – statutory, voluntary and private, as well as their own experiences of giving and receiving care. We start by outlining the health and care needs that our participants described, and the ways in which these impact on daily living and well-being, before looking at the experiences of health services and care support.

People spoke about different aspects of health and the ways in which health, their own and close others, impacts on other areas of life. Participants described the impacts of ill health, on relationships and experiences of loss; managing long-term health conditions which can mean changes in stability and uncertainty due to fluctuations; adapting, coping and adjusting; needs for help and assistance because of ill health; fears of ill health in the future and being taken ill which can impact on the way they live in the present.

Impacts of ill health and disabilities on well-being

Many older people were living with health conditions that affected their daily life. For some these were chronic health conditions that fluctuated and involved learning to assess and adapt according to changing needs. Long term conditions had variable impacts on well-being, often depending on the severity of the conditions and the amount of support and resources available. Health featured as an important factor which participants discussed in relation to well-being:

> Has my sense of well-being changed over the years? Well I think it does ... in a way, because with me again it is the health issue ….and needs, you know. I have chronic conditions so it is not like something that comes and goes you know, and therefore you are also battling with, in my case, I have been very ill since last July with additional things hence the haul out at the hospital yesterday. And emergencies and so on. So all of that is on top. So obviously your needs will change in that way won't they? Yeah. So I get very, very drained a lot of the time very drained. [Kathleen, 67, single, own home on own]

> But it [arthritis / hip and knees replacements] doesn't stop my well being, but just not being able to rush around like I used to and go for as long walks and that sort of thing, and I can't swim in the sea anymore because of the stones, if it was a sandy beach, I probably could still swim. [Ruby, 84, married, own home with husband]

Deteriorating health and disabilities had changed some participants' capacities to engage in social life, and had impacted on relationships with those around them. This was the case in relation to those affected by communication difficulties, such as hearing and speech loss. For example, deafness can have a profound effect on how sociable a person is able to be. Those with hearing loss may become alienated from others in social situations and this can lead to withdrawal.

> And so sometimes I feel … with being deaf, I find deafness has… I don't like being deaf at all and I feel I'm half what I used to be in a sort of way in a group situation and you can't entirely hear what's said, even with the best hearing aids…. One-to-one is fine … but in a group situation, unless you know what the subject is that's being discussed, and also it makes it so I can't be on committees anymore. I used to be on the committee here and I've done a certain amount of committee work here and there in my life, but unless you can hear clearly what people are saying, you're just a nuisance. Yes, I don't feel I can't take part in things at all. [Ruby, 84, married, own home with husband]

Following a stroke communication difficulty contributed to Violet's frustration at her reduced capacity to engage with others and the world around her:

> Yes I could speak but it just deteriorates and I say this last year I've, perhaps if I say, if I speak slowly I won't make any errors but sometimes it's... I get, it's so difficult to explain it. ... It's altered since I had the stroke as you can imagine and so I'm limited to reading the newspaper or looking at the television, you see I can't even walk and that I find that so frustrating ….But because when you do things in the house and that life more or less has stopped…. But no, it's a pure frustration not being able to do anything, oh. It covers the whole thing. …Yes. But you can't do a thing so. [Violet, 90, married, own home with husband]

Many of those who had experienced either acute or chronic ill health described the impact not just in terms of the physical effects, but also of emotional and psychological impacts. These included a loss of confidence and self control. Many said the lack of confidence following an illness had generated a degree of fear, for example of going out alone, crossing roads, and negotiating public space and places. This may be compounded by loss of sight or other physical disabilities. The following examples show how feelings of vulnerability can have a significant impact on recovery and rehabilitation following illness:

> But of course, the operation on my eye which caused my blindness went wrong, I lost a lot of confidence with that.....my balance is worse because things are out of focus and same as with dull weather and dark, I am terrified in the dark, I have to have tremendous help. .... I mustn't go out in wind or rain cos it wobbles my legs too much. If it is a nice day what I will do, take my shopping trolley out and walk up the road and I have got over the fear of the car park spaces … So I still haven't got enough confidence yet to dare to cross the main road unless it is with someone. [Elsie, 81, widowed, own home on own]

> you are more tentative and also you're more aware of how vulnerable you are, I suppose when you go out and about. Because it was so simple, I was just, I just stepped down off a step about that high and just went over, I didn't even fall flat, I just went over on my hand and knees, and that was enough to break my ankle. [Sally, 67, widowed, own home on own]

> But of course with this leg playing up, was now weak, the one I relied on, when I walked up the road which you can see is a long road, went to cross-over, it gave way and, with my shopping trolley, and I nearly went in the middle of the road which terrified me. And I managed to get across but the fear of crossing back over again just lost confidence. [Elsie, 81, widowed, own home on own]

It is clear from participants' accounts that a combination of factors can make a difference in living with health conditions. These include the amount and type of support that is available, as well as managing the psychological aspects of ill health, such as fear, anxiety and vulnerability, and the extent to which these can be shared with others or are shouldered alone. This may apply not only to existing health conditions, but also fears about anticipated future health problems. Feeling fearful can be worse if there is no one to discuss it with, as well actually dealing with illness when you are on your own.

> I'd had another really very, very serious relapse and … I was told I should have somebody there. How do you produce somebody out of a hat? You know, it's just that … you don't just produce somebody to be there because you need emergency health and treatment. [Kathleen, 67, single, own home on own]

> A couple of times when I've been ill at night time I've been aware then, suddenly, of potentially, ahead of you, when you don't feel well, the fact that you're on your own, but it hasn't bothered me, it hasn't happened enough. [Susan, 73, divorced, own home on own]

Joan, who had cared for her husband for a number of years before he died, reflected that coping with illness can be very difficult even if you have a partner and how much harder this may be if you have to face these things alone.

> And when it is happening to you … when it is happening to your partner, you can see it happening obviously, you can stand away from it a bit but it must be very hard when you are on your own, struggling .Or if one is, is much older and your partner gets an illness, how hard to know what to do. I can imagine that would be very, very difficult. It was difficult enough for me when I was in there. [Joan, 74, widowed, own home on own]

Like Joan some other participants had partners or spouses who had experienced ill health and the implications for caring for others are explored in detail in the next section on care. The following examples illustrate that health of close others, as well one's own health, can create major changes in daily life and impact on well-being:

> My husband had a bad stroke, this is the fourth year since he had it, and it's, it changed our lives completely He went into the hospital as a strong man with a good memory and brilliant intelligence and he came out with quite a few losses. Particularly memory and he can no longer drive, loss of hearing, loss of sight, terrific loss of confidence. [Jennifer, 76, married, own home with husband]

> … he has a respiratory condition which renders him, very, very breathless, extremely breathless… everything that he ever did has been stripped from him. He did a lot when we first moved here … and then all that is taken away from him…. Each year it's worse and so therefore also, as I was talking earlier about emotions, it goes through different stages. [Rose, 69, married, own home with husband]

Giving and receiving care

At the time of interviews some participants were carers or had previously been carers for their spouses. Others were receiving care and support from family members and friends as well as from formal care providers. The experiences they describe cover many aspects of care. For example, carers spoke not just about the things that contribute to their own well-being as carers, but also what contributes (or detracts) from the well-being of those they care for. Their descriptions convey some of the complexities surrounding giving care, for example, different motivations to care, responses to situations where care is needed, tensions in the relationships in which care is given, and managing own needs for support whilst giving care. We gain an equally complex picture of what it feels like to need care, for example, difficulties in acknowledging those needs and accepting help, not wanting to be a burden or lose a sense of independence and control. In these accounts of both giving and receiving care we can see significant emotional aspects, such as changes in self identity, sometimes involving a reversal of a previous role in a relationship, as well as the practical aspects of care. What emerges are the ways in which care can contribute to well-being depending on the ways in which it is given and experienced. It is also clear that care can encompass a range of activities and relationships, from having someone watching out for you, help with household tasks, to nursing and personal care – all of which featured in the experiences of the participants.

Half of the participants were over 85 years old and many needed some form of support. Connie described the help she receives from her daughter:

> I don't need somebody on my back all the time. They are next door and I see them lots of times in the day but there are also times when they're gone out in the morning and I don't see anybody for hours. And when you get to 87 you find that you have lost a lot of friends. So you can't ask for caring or things like that. So you can only speak for yourself: caring is someone to keep an eye on you, which I have. So I then had a month in hospital. Then when I came out of course I needed care because I couldn't even – I mean, if she wasn't there I would've had to have nurses, but I mean I couldn't even get in the shower because you couldn't do anything. So she used to come every day and wash me from top to bottom and do everything a nurse would do. So if you say care: that is care. [Connie, 87, widowed, own home on own]

The importance of knowing that care is there in the background if needed was echoed by others. This not only offered a sense of security and comfort, but also reflected the importance of keeping a sense of one's own neediness low key. It was a way of balancing those tasks that you can still do yourself, and those you need help with. Whilst others in the study also had support from family members, many also described a reluctance to ask for or accept help from their adult children. When you have been used to being the one who is giving care, it can be hard to acknowledge your own need for help. Some try to resist this and refuse to accept care from adult children.

> he is my next of kin and that was the number I'd given and she said, oh we're sending your mother home and she'll need to be cared for and I picked the phone up and said, [name], just stay where you are my boy, there's never been an occasion in my life when I'm going to disrupt your life and lifestyle to come and look after me. If I need any help I'll get it some other way so you do not come home. [Pam, 79, widowed, sheltered housing on own]

> As you can imagine I feel very, very upset for [husband] having to look after me and really he's not getting anything out of being retired. [Violet, 90, married, own home with husband]

> I don't ask anybody for anything. I'd sooner crawl round the floor than ask. ...it's just that I don't like asking. I don't like asking. I just feel that I'm being a nuisance – that's the word – and I don't want to impose. Because I'm old, I don't want them to think that I'm...you know? So I mean I never ask the family to do anything, not a thing. [Grace, 97, widowed, own home on own]

The reluctance to ask for help was often described in terms of not wanting to be a burden on loved ones. For some people there was also a fear of rebuff or rejection. There was an underlying sense that accepting help could also entail a transition in self-identity and shifts in power, authority and decision-making within the relationship. The idea that needing help or support equated with becoming a 'burden' was a recurrent theme in many accounts and was often linked to wanting to maintain independence.

But many participants who had recognised their needs for support found it hard to access appropriate help. The availability of information and advice about sources of help, and people's feelings about asking for help often combined to make it hard to find the help they needed. Not knowing where or how to find trustworthy help came up in many accounts:

> Sometimes I'd like somebody to come in perhaps once a fortnight to sort of wash the paint, do that. The difficult things. But I wouldn't know where to go to find a reliable person. [Grace, 97, widowed, own home on own]

The ways in which requests for help were responded to affected feelings of confidence about asking for help in the future. Jacob recounted an incident with a neighbour that had left him feeling embarrassed and determined not to ask the neighbour for help again:

> she goes shopping once a week in her car, she said to me, look if you want any shopping done, all you have to do is let me know and we can go together and do some shopping. It so happened, soon after that, when [wife] was in hospital I wanted some help and I went to her and she said I am so sorry, I can't do it this week, I'm busy. [Jacob, 96, married, own home with wife]

In contrast, if the request for help and the support received is positive, it lessens the sense of feeling a burden and becoming disempowered by the interaction. Grace compared being taken shopping by her son, which she described as functional and rushed, to the altogether different experience of being taken by her friend's son who clearly enjoyed the experience of shopping with her:

> When [son] takes me it's the nearest one and back again, we're shopping, back, he dumps the shopping and he's gone. Within an hour it's all over. But with [friend] he says 'no, we'll go out to Tesco out at [place]' and he treats me. I just feel like the queen! .... Well you see I look forward to going to Tesco with[friend] because he's so...there's no.... when I go with [son] he rushes you and out, with [friend] he says 'now, listen, we've got all the time in the world and we'll take our time'. And he'll look at that and say 'ooh, that's a bit expensive, here look at that one'. [Grace, 97, widowed, own home on own]

Receiving care from family can contribute positively to well-being. Mary, who has learning disabilities, had experienced living 'in care' throughout her life in institutions. She reflected on how her life is better now she lives with a family who are her carers:

> But, I mean I've had a rotten life since I was little, I mean I've been pushed around a lot, you know, pushed around from home to home and now I'm settled, now I'm with [name]. So, I mean I've been with the family now, and August the first this year I'll have been there two years, so that's not too bad, I mean I've never stayed anywhere that long before, I hope to stay about 20 years and that's it. ... Every night I have a shower, it's lovely really, I've got my own bedroom, so that's good, yeah, it's a lovely, it's a lovely environment that is, so I'm just glad that I moved there. ... I'm much happier than what I was down there. Everybody that comes sees me down there now, "God, haven't you changed?" you know. [Mary, 75, single, lives with carers]

The different experiences of asking for help and receiving care from family members reflect similar experiences in relation to paid care. We discuss this below.

Becoming a carer

Some of our participants were or had previously been carers. They spoke about their experiences of becoming a carer and adapting to changes it involved, for example in their relationship to the person they cared for; the impacts of the caring role and dealing with the emotional aspects, for example feelings of guilt and duty as well as satisfaction and love; the actual activity - the 'labour' involved in care; as well as experiences of seeking help and support for themselves and those they cared for.

Our respondents recounted different experiences of becoming a carer. Some took on the role gradually as a partner became increasingly frail or unwell. For others, like Jennifer it followed an unexpected event. Jennifer's husband had a stroke, and this brought extensive and far reaching changes which were unexpected and difficult to adjust to:

> Just feel that like ... we ... you always think that things are not going to change, that things are going to carry on in the same way and it's such a shock, and it's so frustrating. The most frustrating thing is that normally when you look after somebody they get better. That's the most frustrating thing. [Jennifer, 76, married, own home with husband]

Older people respond differently to both giving care and becoming a carer. Some spoke of difficulty adjusting to changed relationships between carer and cared-for, as well conflicting emotions on taking on the role of carer, including guilt and a sense of duty.

> but I do find it very difficult looking after him because he will not comply. And also, there'll probably be others that you talk to that are in a caring capacity that might agree. I'll say something to him and I get the feeling he's just listening to that sound of my voice, not the words, just the sound. And then the doctor will come or the District Nurse and they'll say exactly what I've said and he's actually listening and he'll tell me afterwards what they said. And I think I've been telling you that! It's so frustrating you know at times. [Rose, 69, married, own home with husband]

As we noted above, receiving care from spouses or adult children may entail a reversal of roles and care giving can also encompass role reversals. For those who had lived with traditional husband and wife roles this challenged their ideas and expectations of themselves and their spouse:

> But what is a big problem is that I have to do all of our jobs, every; [husband] used to have a traditional male role, and he did cars, garden, finances and I did the female role of socialising, inside the house and keeping in touch with everyone and buying all the presents and organising all the occasions ... It is all mine. Every decision is mine, every problem is my problem. And there are some things that I just hate like car tyres. [Jennifer, 76, married, own home with husband]

> I think my husband being as healthy as he can be with a lot of things wrong is usually the biggest problem that I ever have to face and I'm not a good nurse and I'm not patient and I hate having, if we arrange to see friends, having to cancel out and he's got a lot of things wrong with him and I do find that very difficult. So he's had a rotten deal and if he's not well he obviously wants a lot of attention and I suppose for many years I relied on him, I mean I rely on him to….he does all the money stuff and the books and stuff like that and I find money has been a big problem. [Rachel, 74, married, own home with husband]

Although looking after a loved one could mean a lot of hard work and often involved personal sacrifices and giving up other activities, some people described pride and satisfaction in undertaking this role:

> it was a fulltime job, yes, in the end, it was fulltime, because he was fed by a pump, he had a peg and everything so it was very much a fulltime job and I was, I suppose, fussy in a way because I never left him really, only….this girl that I became really friendly with she was the only one I would leave him with ... he never went into respite at all, never, the whole time … I wouldn't trust anybody I felt that what my expectation of what I would like, why shouldn't he have the same so I made sure that he had it. He was clean and he was looked after…you know all the things that he would like, he'd like his aftershave, he used to have the nicest perfumes and the children use to buy him all these sort of things so that he was always beautifully turned out and always looked nice, even though he couldn't walk or anything [Sally, 67, widowed, own home on own]

> I miss not, I miss having someone to care for in the house. I mean caring for my husband the last, well five or six years it has been quite important, and I do find that a sort of gap ... and I miss that. Yes, I miss not having somebody to care for. [Joan, 74, widowed, own home on own]

In many cases part of the role of carers involved finding services for the person they cared for as well as support for themselves. This could entail negotiating previously unknown areas, such as getting assessments from social workers and finding out about entitlements to financial support or services:

> The trouble with, with being in a situation like this is every carer has to pick up what information they can from each source. There is no central source. There is no carer's manual which there should be. [Jennifer, 76, married, own home with husband]

Jennifer's account demonstrated that it is not just a matter of finding out what is available in terms of support, but also making sure that support would be appropriate:

> several people keep saying to me I should find respite on a regular basis which is good in theory but I have yet to find a place that I would be happy for him to be. And do you know, no one can help you with that. It is a very personal choice. [Jennifer, 76, married, own home with husband]

Those caring for others also need support for themselves. Some had their own health problems and were concerned about not being able to continue in the caring role. Carers can find it hard to ensure their own needs are met:

> this is what carers do, they talk about the cared for one instead of themselves … I, my health has deteriorated since becoming a carer … and I've been having sort of backache twinges for a while and you ignore them … You put them at the bottom of the list. [Jennifer, 76, married, own home with husband]

> a couple of days later they wanted to send him home and I said 'look I've got this virus and I'm not well … he said 'oh well don't worry it'll be alright'. So I said, 'well, what do you mean it'll be alright … he was in hospital and they wanted to discharge him … the next day they telephoned me and would I have [husband] home it they contacted the crisis carers …. And I couldn't do anything else but agree. I find it difficult saying no, you know. [Rose, 69, married, own home with husband]

Health and care services and service providers

We have already seen in the section on **People** that relationships, and more specifically the quality of relationships, can have a big impact on well-being. At a fundamental level giving and receiving care or support of any kind creates a relationship, which at its best can be supportive, or conversely can be negative or even damaging. In looking at the ways in which participants described their relationships to those who provide health and care support it became clear that values such as reliability, reassurance, trust and respect, determined how help was experienced. Interviewees recounted many stories about health services and those who work in them, particularly GPs and nurses, and identified examples of good and bad practice in relation to professional providers. We examine these to look at the factors that made a difference.

Many had regular contact with health care services, in particular GPs and local surgeries. Participants valued good access to GPs and services (both in terms of location and appointment systems) and feeling that they had been properly listened to by practitioners.

> I've got the most wonderful surgery and doctors here … he was due to start that week and I always remember he phoned on the Monday morning, introduced himself, and said 'can I come to see you at 1o'clock?' And he was with me the whole time that [husband] was ill, because I had him upstairs for six months with the hospital bed with nurses and what have you. When [husband] died, I thanked him and said 'I don't know what I would have done' and he said 'now that is over, I am going to look after you'. And he has….. [Connie, 87, widowed, own home on own]

> … She[GP] said, 'oooh we never do the better knee' and I thought 'oh, just listen to me woman' but you know she didn't … she didn't listen to why I would want the better knee

> done, most normal people wouldn't, so you'd think I had a reason but she didn't actually [listen]. [Margaret, 83, divorced, sheltered housing on own]

> I think the NHS communications is terrible. And I've talked to quite a few people and they all agree with me. Doctors, then nurses and people who work in that profession. There's a certain part of the doctors where they still, I think, cling to this business of I'm a doctor, I know more about it than you and therefore you should take notice of me, what I'm saying. [Peter, 74, single, housing association on own]

Some participants described confusing changes to appointment systems. This varied from surgery to surgery and many found new arrangements less satisfactory:

> … everything has changed. You see at one time you could phone the surgery, 'I want an appointment' and you got it. Now you can't. You don't get appointments anymore … you get the doctor ringing you and asking you what's the trouble and then it's up to her. [Agnes, 86, married, own home, with husband]

> The doctor we go to … they've gone downhill a great deal in the practice .....our doctor is sort of semi retired because …I believe with the huge increase they gave him... it made it possible for him to retire or semi retire ... he's still doing private work I notice.....but it takes at least a week now to see your doctor and we can never actually see the one we like to see. [Focus group 6]

Others felt that the decline of the old family doctor who knew you and the increasing use of technology to diagnose meant that relationships with GPs have become more distant and treatment is often now provided by nurses:

> It's a different kind of medicine today. The general practitioner today does not act as a doctor per se … they have highly sophisticated computers and while they are listening they are tapping their keys … it's all mechanised. Doctors today never give a patient an injection. You've got to be lucky indeed if they take the blood pressure more than once or twice. If there is anything that requires physical effort, then the practice nurses will do that and they are very highly qualified nurses. [Jacob, 96, married, own home with wife]

For some accessibility related to location and appointment times, which often did not seem to take account of the particular difficulties older people may experience. For example, early morning appointments were problematic:

> every time I rang them to arrange the operation or something, they said, can you come in at seven o'clock? And I said, no. And imagine having to sort of say, why? And I don't like to use my age at all because I don't feel seventy-four but, you know, you want to say, hey, I'm not a young sprightly young chicken who can get up at five o'clock in the morning, you know...I said, look, there's no way I can, public transport or anything like that, I mean, it was all kinds of things. I said, look, there's no way, no way I can physically get here because there's no buses at that time, A, I mean, I really am terrible in the morning that's why I said to you... I really am, I mean, it's not just being lazy, you know, I just am drained of any kind of energy in the morning. [Peter, 74, single, housing association on own]

> they have now got a new clinic out at the back of [name] … so we have to go up there … but there isn't not one bus that goes up there … you can't get there by public transport. [Agnes, 86, married, own home with husband]

> We went to the poly clinic this morning, my wife had to have some scans done for

> kidneys and we should have had transport, hospital transport, but we didn't get it so we get a taxi and he comes and he takes us there and when he gets there he stops there and we have to open the doors, we have to get out. Now that's difficult. I have had some bad falls getting out of taxis...it is terribly important to us getting assistance in and out of transport. [Jacob, 96, married, own home with wife]

Underlying many of the experiences – both positive and negative –was the quality of the interaction and relationship with the member of staff (whether GP, nurse, receptionist or consultant). Some participants felt disempowered in their dealings with health care staff. Whilst some felt able to challenge staff, others feared there might be repercussions if they complained, such as having a service withdrawn or asked to leave a surgery.

> … through her [GP] I have lost the sight of one eye and she's changed now and if we phone she just gives us attention though we were at one time we didn't want to bother her too much because we are old, and she could easily ask us to leave and who wants to take on old people? [Richard, 89, married own home with wife]

> I don't like to complain about my doctor in case I get taken off their list.....because they want to shorten their list. [Focus group 6]

> My doctor's a bit dogmatic. He doesn't appear to be user friendly but you have to break him down and give as good as you get with him and then he's alright. A lot of people don't like him … but I like him. [Charles, 79, widowed, own home on own]

> … I don't like the feeling of being patronised … in the end I hated her … I did say something to the doctor about her and he said she'd done most of her nursing in the army and I said 'yes and it shows' … she shouldn't be let loose on old people. [Margaret, 83, divorced, sheltered housing on own]

> So, it is difficult, you never get the same one [podiatrist]. I think this woman I had last week, in fact I have seen her before, but she says herself she's part-time you see, this is what happens I think. Anyway, that's the health service… they should have records of that they, you know, comply with, but each person doesn't seem to know what the other one did before … the next appointment you'll see someone different and … there doesn't seem to be any sort of continuity at all. [Agnes, 86, married, own home with husband]

Expectations of the quality of services varied. These were partly shaped by public perceptions and publicity around poor services, which may contribute to a reluctance to access services, in particular residential care.

> I did barrier nurse at [name], they don't do it, they don't even know what it means … there's a doctor and he's sitting there … the pencil goes in the mouth, goes down. Right, he gets up, goes off to see somebody, somebody else comes along and sits down, gets hold of the pen and you think 'oh God!' They just don't think … they really don't. And things like banister rails, light switches … God! They just don't'. [Rose, 69, married, own home with husband]

Feeling secure that good health services will be available when needed was based on positive experiences for some:

> …even hospitals are better – people will not give them credit for the work they do but I know because I've been in them and have firsthand experience … if you've got life-threatening illnesses you are dealt with there and then but if you're walking around with varicose veins you've had for 50 years already you'll get them done when they've got

> time to do them or the strength to do them You cannot beat the National Health Service for getting things done when they need to be done. [Pam, 79, widowed, sheltered housing on own]
>
> … for the first couple of week I've had the nurses come in … You can get help, there is an awful lot available. It makes me cross when they say there's not. [Connie, 87, widowed, own home on own]

There was similar variation in perceptions and expectations in relation to professional social care services. Many had experiences of statutory social care assessments, either for themselves or for those they cared for; some had care and support from the private sector and almost half the participants were receiving (or had received) some form of service from Age Concern. The help received ranged from 'low level' support, such as nail cutting or help with shopping and household tasks, through to personal care, attending day centres and residential care. Many themes and issues relating to health care, such as information and accessing services and relationships with providers, were reflected in participants' experiences of social care. Participants described what they valued when accessing and receiving social care services, as well as concerns about their own future care needs.

For those receiving statutory social care services it was often the first time they had come into contact with services and negotiated the system. They did not find it easy to access information about services or local authority support and there was some uncertainty about rights and entitlements in relation to social care services. Responses suggested awareness that resource constraints could cause considerable delay in them getting help, and that a failure to provide any feedback to requests for help could leave people feeling that their needs were being ignored.

> We did get direct payments to help defray some of the costs, but it took quite a long time before I discovered that that was available...I was tapping into all the agencies that I could for support. ... You need to be articulate and have the energy to push in lots of cases. It's quite hard... obviously there are leaflets and things, I mean the GP should be the person who tells you. In our case it was the Parkinson's disease nurse specialist who was a key, who played a key role in, sort of coordinating our care. We had a Parkinson's support group who would share information so I think self-help support groups have been very important. [Joan, 74, widowed, own home, on own]
>
> I did not get an assessment for about two and a half years. That is because the assessing staff is extremely short staffed, the person I saw eventually couldn't have been better, more efficient. I couldn't have admired her more but she was overwhelmed with work. [Jennifer, 76, married, own home with husband]
>
> it's difficult... how to find other services. I've had, we've had social services here quite a bit and questionnaires and getting information and that kind of thing and we give them all the answers as we could and they got up and shook hands and said goodbye. Nothing has come of it. [Jacob, 96, married, own home with wife]

Again, what appeared to make the difference in the way that care services were experienced was the relationship between the person providing the care and those receiving it:

> When my husband was ill I had a lot to do with the social services, yes, I had carers in who used to help me shower him because I showered him every day, so because he couldn't stand I had to have somebody in. So yes, I was very lucky, I had very good help. There was one particular helper who used to come all the while and she became like a daughter to me and she was a lovely and she was very distraught when my husband died. .. I was very lucky. I know a lot of people have had bad experiences … but I think

> that I was…. I mean to say that I could have lots of complaints about social services but the actual people who came to help me with my husband were very good. [Sally, 67, widowed, own home on own]

Participants had also experienced care and support services from non-statutory providers, such as Age Concern and CareLink (some of these services are commissioned by statutory providers). These included ongoing preventative support such as nail cutting, help with shopping and household tasks, as well as interventions for more serious needs following a fall or a stroke.

> It's actually itself a wonderful service and we are sticking with them because we want help you know, and they are very nice about it and supportive...to help people to spend their days in how they get on in the household and getting up and making food and cleaning and going shopping and that sort of thing, Age Concern have certainly helped us, certainly helped me in doing this [Jacob, 96, married, own home with wife]

> I wanted nail cutting cos that's another thing I can't do. There's not only my feet but I cannot even do my hands because I have still got it there, but, and so I went there and I am quite friendly with the girl who cuts my nails. She is very nice. [Agnes, 86, married, own home with husband]

> [following a stroke] … for six weeks he walked with me, helped me cross over the roads, fussing me, hold your arm cos of my sight you see, cos see without going into the road … then gradually after a time I let his arm go … Yeah, it was very good. So after six weeks he stopped and he said now, he was very, very polite, marvellous man, he walked with a lot of people and he said if you want more help I am willing to come back. [Elsie, 81, widowed, own home on own]

> That's called Carelink …one morning I woke and I felt pretty ill. And I pressed that. It was wonderful. Very clever. Operators on the phone … they are wonderful really within 15 minutes an ambulance was here … and they shot me up into the hospital. [Samuel, 88, divorced, private rented on own]

Some interviewees attended day centres which provide activities and lunch. Some day centres were statutory and one was provided by a voluntary sector organisation. People who used them enjoyed the opportunity to take part in activities which included talks, scrabble, quizzes, exercise, art, poetry as well as occasional outings. As with other services, the relationships with the staff were considered important:

> They're very, they're lovely staff here [day centre]. I think we're very lucky, I've never seen them lose their temper. I know they're not supposed to but I mean often I give somebody a clip round the ear. We're so awkward old people, we don't mean to be but you know, it's one of those things … old age. [Ethel, 96, widowed, sheltered housing on own]

> They [day centre staff] do ring up to say "are you all right" if I haven't said that I won't be coming in - they do check and they're very nice - it's a very good place. I'm glad I found it. They try very hard because there's not many of them and it's voluntary ….it's a charity is what I mean. There's a few paid workers there. I think they try very hard. I've never heard of a better one. [Margaret, 83, divorced, sheltered housing on own]

There were concerns expressed by some that recent changes in the organisation of local authority day services had a negative impact and stretched resources:

> I look forward to coming here …But I do believe they're getting too much on their plate here, too many people come at the same time. It all started all with [name of day centre]

> closing down and they all come here you see, well I think they've got enough places to put other people in to shorten the load here. But other than that, they're pretty good…. [Albert, 89, widowed, sheltered housing on own]

Many participants were worried about the cost of care services. People spoke about their uncertainty and anxiety about meeting eligibility criteria, and although many were planning financially this did not always give a sense security because of fears that expenses may be beyond their control:

> ….they ask you what you've got in your bank and just because it's over...we had to pay for the carers...the bill for care every month, I mean, that's £2000 so....I honestly get a bit worried because you think £2000 in a year that's 12,...it's £24,000 a year, isn't it? [Violet, 90, married, own home with husband]

> ...I called in the, [name of hospice] have an at-home care service and I rang them.... The charge is tremendous.....if he goes into a care home it is all done.....I thought that was such a good idea at the time when I looked into it but it worked out about £2,600 a week... [Jennifer, 76, married, own home with husband]

> ...I have done some research.....I'm not going to get any accommodation for under, which is worth anything, for under £700 a week.....If you go into residential accommodation and the sort of sheltered life prolongs your life, then you have got to be a little careful..... we can't rely on anyone else....And then again, being more realistic, you have to say to yourself how long are we both likely to exist? How long are we likely to live? [Jacob, 96, married, own home with wife]

Concerns about future care needs related not only to cost, but also to the quality of care provided within residential homes. For some, like members of the focus group with BME older women there was concern about communication and language barriers and the degree to which cultural and religious needs, for example in relation to food, would be met. Some anxiety was based on negative perceptions rather than actual experience:

> I'm scared of going into homes. My solicitor frightened the life out of me, you know, not, you know, she comes now and then, not very often and she was saying some of the, this home she goes to for one lady they put them to bed at 4 o'clock because the staff want to go home, and I thought "oh dear, I do hope it doesn't happen to me" and, you know, feeling well it's hard, I wish I wasn't you know… because it does worry me. I wake up of a night and I think (gasps) "oh dear, if I'm put in these places and left to get on with it, how awful". [Ethel, 96, widowed, sheltered housing on own]

A number of interviewees and focus group participants did have experience of residential care, either for themselves or a spouse, and their views were mixed. They spoke of medication not being administered and residents being found unwashed and left unfed. One participant whose wife had been moved to a home where he felt confident the staff here really looking after her, offered a more positive perspective:

> They [the staff] say oh she's nice. They like her, they get on with her, they tell me. … all the staff they all know her, they all get on with her you know, and the staff's alright, one of them, he's a nice bloke, he is very helpful, he comes up, he says oh don't worry. You know they know what they're doing, the staff know what they are doing it's more now, settled with me now knowing that she is being looked after so I am more settled in myself. [Eddie, 85, married, council rented on own]

Variation in the quality of the care was reflected by Jacob who was considering a move into residential care for himself and his wife and had visited two different homes:

> we did a visit sort of research visit, and we spent a week with them and it was wonderful. Everyone was nice, there were about thirty odd of us and we all ate together in one dining room, the food was good and wholesome, and it had a lovely library and so on. It has a beautiful garden and the weather was nice and we could walk in the garden. [Jacob, 96, married, own home with wife]

However, they stayed for a week in a different home and had a very different experience:

> we were very unhappy and we were very, very glad to get home. It was very expensive too. But when we went down to the dining room the waiting staff were most uncouth women for them who obviously disliked all the people they were serving and did everything they could to make life difficult. And I'm not exaggerating. And we got upset... the atmosphere there was as if you were in a prison. [Jacob, 96, married, own home with wife]

A different set of experiences were reflected in the focus group we conducted in a care home. We asked those who took part if there were things about living there that contributed to their well-being. Many felt that that the physical surroundings and facilities were very important. All of those who took part in the group had mobility difficulties and used walking frames so accessibility, having enough room to move around easily and lifts were greatly appreciated:

> We have a lovely garden to walk round which has special paths you can manage. [Focus group 6]

Residents felt staff recognized the importance of being able to make decisions for yourself and having choices. This included having a choice of food and offering an alternative and choosing to eat with others or in your own room. Some liked to watch television with others in the communal lounge, whilst others preferred to watch in their own room so that they could choose which programme to watch.

Many residents were frail and needed a quite a lot of support. Some commented that it can be hard to accept help when you are used to doing things on your own. However, they felt if help is given in a caring way it makes all the difference:

> Modesty files out of the window and you have to accept it... you have to get use to it, no good being coy and shy...and it could be quite dangerous if you don't have help....but you couldn't have a more caring place really [Focus group 6]

> The staff always respond if you ask for something though they are always very busy and you can ring from your room if you need help

> They are very forbearing here the staff...so many different personalities to cope with...it's amazing that they cope with you, your foibles.... [Focus group 6]

Participants' experiences show that ill health, disability, needing care or being a carer all present challenges to well-being. However, these things in themselves do not prevent well-being and the ways in which people described adapting, overcoming and adjusting demonstrate this. What is also clear are the things that can make a big difference to what it feels like to live with ill health, or simply needing some support with daily living. The ways in which health and support services are delivered and the ways in which care from family, friends and neighbours is experienced, profoundly affect whether being unwell or in need of care and support, compromises well-being. The nature of interactions between those who provide services and those who receive them is fundamental to whether or not the interaction is experienced positively. When health and care services were underpinned by values such as respect, reliability and reassurance, and where trust

was present, the person receiving the support did not feel disempowered or de-humanised as a result. The quality of the service was identified by many participants as important and this included staff skills; time given; flexibility and sensitivity.

4.3 Resources

In this section we look at the kinds of resources that can impact on well-being. In the previous sections we outlined some of the challenges that can accompany getting older, such as increased needs for support due to illness or declining health, and we have already discussed the significance of people and relationships for providing support, a sense of belonging, company, and shared interests. Here we reflect on what older people told us about other things that can help, as well things that can hinder their sense of well-being. These include **personal resources** such as resilience, being able to adapt to change and draw on life experience, as well as **practical resources**, such as money, technology, the importance of keeping active and having interests that are enjoyable and help people feel connected and valued. Once again people's experiences were very varied and some of the resources we describe here that could help could also be a source of anxiety and impact negatively on well-being. For example for some people, technology such as the internet, had opened up opportunities for communication and staying in touch with family and friends at a distance. But for others it was experienced as alienating, and generated a sense of being 'out of touch' or left behind. In this section we explore not just the resources in themselves but wider issues of access and how they are used and experienced.

We also asked participants about changes to their well-being over time which invited reflections on ageing and learning to adapt to changed circumstances. There were many differences in the ways people described what contributes to their well-being and how this had changed as they had got older. Perhaps unsurprisingly, these differences often reflected the wide age range amongst those we interviewed. For example, people in their sixties reflected on their experiences of early retirement, whilst those in their nineties were more likely to talk about the impact of ongoing losses of friends and family members. The themes discussed in this section are organised under the headings personal resources, which include things like life experience, resilience and being able to adapt to change, and practical resources, such as money and financial security, technology and activities.

Personal resources

Here we look at the ways in which people spoke about aspects of their personality and outlook and attitudes towards life which helped them manage their present circumstances and to make sense of changes related to ageing. These included reflecting on lessons learnt through experiences over a lifetime, faith and values, being able to adapt to change and plan for the future as well as being able to enjoy the 'here and now'. Some of the tasks and challenges of growing, especially those arising from a major change trauma or loss can often make people lose touch with the inner resources and strengths they have developed over the years. Supportive and respectful relationships with others can help give people a sense of being 'back on the map' and enable them to reconnect with those resources and a sense of themselves as a whole person.

Drawing on life experience

Many spoke quite philosophically that the advantage of getting older was being able to draw on previous experiences gained over a lifetime. People often described this as a kind of learning, perhaps from past mistakes, or reflecting on the benefit of hindsight, and the ways in which this informed their present attitudes:

> One thing I have learned about living well? I think to make the most of each day, count your blessings I think. I think education is key, is paramount. Accept you are a fallible human being and you are going to make lots of mistakes...I learnt...that you create good luck by a lot of hard work...and you have choices. You can make good choices and you can learn to be happy. I have learned to accept myself as I am and not to be so critical, self critical ...there is nothing you can do about the past, so why are you beating yourself

> up now? Or in the future, you only have today, we don't know about the future so make the most of it.....basically I have an optimistic out view. [Jennifer, 76, married, own home with husband]

> I feel quite sincere about this that too many people worry about what's happened in the past and there's nothing you can do about the past. Nothing you can do about it at all. It's gone, I mean, past is very useful, of course it is, but as far as doing things the past has gone, you know… I can't do anything about it and it's no good, oh dear, woe is me; you just have to get on. [Peter, 74, single, housing association on own]

Some described how they had learnt to accept themselves and become more tolerant of others and suggested this has a positive impact on daily life and relationships:

> When you are young, nothing about you is right and you take everything personally whereas when you are older, you learn to make more allowances for people ... I always, I always give the benefit of the doubt rather than jump to conclusions, [Jennifer, 76, married, own home with husband]

> I think in later life I have realised it pays great dividends to be nice to people which I wasn't when I was young... Ah I think, the older you get the more important they [relationships] are. I am easy going and affable now. [Charles, 79, widowed, own home on own]

> I think ... tolerance as well and letting other people live their lives and not interfering....I think I've always had it but I think...I've become a lot more tolerant [Sally, 67, widowed, own home on own]

For others, memories of past experiences were another type of resource. Thinking back to earlier years and reminiscing generates a sense of pride at past achievements and positively contributes to self-identity. This was affected by the opportunities that people had had, that were not available to everyone.

> We used to go and do all our ballroom dancing which we got all our medals for, which was lovely. So I have got all that to look back on ... We were dancing twice a week...They were lovely days. I've got a lot to thank for....I mean the only feeling I get is looking back on what an interesting life I've had. Very happy memories. I mean, a lovely husband, I mean he was the one and only, which is unusual today. [Grace, 97, widowed, own home on own]

> I suppose the greatest pleasure we had, was the fact that once we had retired …we have travelled an awful lot. We did go to lots of countries, hire a car and do our own thing. I think that that has been extremely enjoyable. Very uplifting and you see other people's points of view ….immense pleasure to remember …..In fact that grandchildren are, you know, where else are you going to? Or have you been there. Or speak to gran and granddad, they have been there. [Agnes, 86, married, own home with husband]

> I loved the time when the children were all… well, all their lives but when they were teenagers and when they started going to university and they would always bring, our house was always full, they'd always bring all their friends home from all over the country and so they'd come to stay for weekends and everything and I used to love that and cooking the big meals and everything. [Sally, 67, widowed, own home on own]

Developing resilience and ability to cope

Some people had developed resilience having come through difficult situations in their past. This helped them develop their abilities to cope with the challenges they faced throughout their lives and as they became older.

> I mean we just make the best of it. You know you don't expect anything to be given to you... It does get the better of you at times. But there is no other option but you've got to pull your boot straps up and get on with it....and the better attitude you have helps you know. [Rose, 69, married, own home with husband]

> I suppose so, but I've had cancer twice, once since I've been here, and I just ignore it. Immediately I get back out of hospital I get my routine back within a month and nobody knows I've had an op....that's the way I work. And I hardly ever mention it. [Pam, 79, widowed, sheltered housing on own]

Others described the importance of trying to keep positive and the ways in which they attempt to do this:

> I have to motivate myself if I am feeling a bit down, I will write a list and have the pleasure of crossing off the list but it takes longer to get through even the shortest list. [Jennifer, 76, married, own home with husband]

> Yes. Oh but um, I can get a bit down so I'm not like shall I say, I mean I can get low and then I think well there's far worse people off, far worse off people than me so I mean to say you can't, you've got to accept it unfortunately but. And I mean let's face it, all over the world there's trouble isn't it, isn't there? [Violet, 90, married, own home with husband]

For those who had lived through WW2, either as a child evacuee or in national service, these experiences were an important reference point, particularly in relation to overcoming difficulties:

> Because it was my upbringing because I was born and brought up in the country and flew in the WAF, and that was the first, during the war you see, beginning, and that was the first shock. But to know that there was another world outside the country. And, more than that, my father died when I was five and my brother was two and I mean, I, I have the most admiration for my mother who coped all those years with us, because she was so determined, I wouldn't be left, we wouldn't be left in the same position, goodness knows what she sacrificed for that. I know it. I know she would never remarry because of the children [Agnes, 86, married, own home with husband]

Faith and spirituality

Some described faith and spirituality as resources to draw upon. We discuss later how going to church and belonging to church groups were also important activities for many people. But having faith and spiritual belief could extend beyond attending church and religious affiliation.

> I love people and I love helping people ... but the greatest and best relationship is with God ... well-being means loving one's neighbour as one's self and loving God with all our heart. [Reggie, 90, divorced, sheltered housing on own]

> I kind of thank god when I get up in the morning … my faith in god is very important, because god has brought me this far, he's allowed all these things to happen …. So many answers that I don't know. But my faith is important and I don't know about the future and I don't worry about the future, unnecessarily, I feel its wasted energy. [Susan, 73, divorced, own home on own]

> And we've always been brought up with religion, so we go to church always, … it's a sort of… whether you believe it or not, it's an anchor, to have a quiet time … Well, it is to me, I think people who never… they may have music or art or something, which probably takes its place to a certain extent, but maybe because I've always been brought up in religious houses…. It isn't really security, it just sort of holds you on course a little bit perhaps. I should feel quite a bit odd if I didn't go to church somewhere on Sunday. [Ruby, 84, married, own home with husband]

Having faith as a resource to draw on as well as providing a sense of belonging also came up in focus group discussions. For some, spiritual and religious life helped make up for loss of other relationships:

> It is important in life [to have friendship] … it meant a lot, but now I have to do without it… my friends have died, and well I can do without it because we have God here, we are very lucky... [Focus group 6]

For others, it was belonging to a community with a shared faith that provided a connection to others:

> The church group...where you have got something in common....you have such a deep shared faith that it is like...a family...you see the same people...you feel part of another sort of family. [Focus group 6]

Learning to adapt to change

Another important aspect of learning that some people reflected they had developed over time was adapting to change. There were many examples of the ways people had learnt to make adjustments as they grew older. Often this was in relation to changes in health and the physical and psychological aspects involved in adapting to new circumstances.

> Your body adapts and you adapt, because you haven't got the energy… I used to love playing tennis and you'd think you'd be fearfully upset but no, your body tells you, you can't do that anymore. I suppose when one is reasonably adaptable, I suppose yes, you just have to get up and do something else. …it's no good sitting down and crying and that's the last thing I want to do is sit in the chair all the time watching television and saying "I'm feeling old" I wouldn't like that. [Ruby, 84, married, own home with husband]

> Right from childhood you are guided in a direction – school – work – marriage – children – and then you come to this point and it's up to you what you do ... so you've got to motivate yourself for yourself ... if you've never done that before and you've always looked after other people you have to learn how to do it for yourself. [Focus group 1]

Sometimes this involved adjusting and adapting so that people continued with an interest even in a different way. This required learning to let go of some things and being open to finding new ways of doing things:

> that is osteoarthritis that has been affected by it, but the spine has been damaged and it unfortunately is gradually getting worse. It has got a lot worse this last year. There are so many things I can't do... Well, it is certainly the garden I love, and I would be very loathe to leave it. I have often thought, well, you have got to face it because I am so limited in some of the things I can do that we have got to give it up but I should very much miss it. And so consequently I garden indoors…. I have got a very good window that likes orchids. The one thing I can do is grow seeds in the greenhouse and prick them out because I am standing. Well, I don't like standing very much but I can do that. [Agnes, 86, married, own home with husband]

Related to the process of adapting to change can mean making the most of the present and focusing on the 'here and now'. Some reflected that life post-retirement had enabled greater appreciation of simple everyday things:

> Well, I mean it's great that you don't have to work anymore. That's good. And every day is a holiday really, I mean, and every day you are not quite sure what every day will bring. There's no, I haven't got a routine. I mean sometimes I eat at 6 in the evening, sometimes I eat at 8 in the evening, I can choose can't I.... It can be simple things like getting up early in the morning and going out early in the morning and you think oh isn't this great to be out here...Getting up early in the morning sometimes you feels it this is good, it's another day. [Charles, 79, widowed, own home on own]

> [husband] and I also meditate, we try to meditate for 20 minutes every day. No official meditation, just sit quite still and think your own thoughts or try and get rid of any thoughts… it does seem like a sensible thing to do just to stop rushing everywhere. … You know, life is very rushed these days actually, I think everything is rushed, people rush around and they want to have a good time all the time, it hasn't got the sort of… they don't even notice the trees, I'm a great tree and flower admirer, I know all their names, I wouldn't just say 'there's a tree' I know their names, you know, people don't hear the birds, they're just rushing through life and I think that's such a sad thing. [Ruby, 84, married, own home with husband]

Thinking about the future and looking forward

Whilst many associated thinking about the future with anxiety and fear, particularly in relation to health and social care needs, some were able to plan for practicalities, and others looked forward to things they were planning to do.

> I think I am always somebody who has wanted to have some project in front that I can work towards and I guess I will soon get to the point where there isn't a project in front that I am looking forward to, so'....so I have to create one I think I will continue to create projects for myself to work on probably as long as I am mentally capable of doing so. [Joan, 74, widowed, own home on own]

> ...and the thing about well-being is the reason to get up in the morning – if you haven't got a reason to get up then well-being is rock-bottom...and you've got to have interests at any age [Pam, 79, widowed, sheltered housing on own]

Many people, like Iris, expressed concern over what might happen:

> Now, there is something that bothers me, you talk about old people, I worry terribly about the future because of what will happen. Ideally, one would like to be looked after if it's necessary, in one's own home but that is going to be very expensive, as is everything else, isn't it, wherever you go. So it's a problem for everybody, I suppose, all old people. I would hate to go anywhere, you know, that wasn't very nice. Yes, it is a problem. [Iris, 88, divorced, own home on own]

Some, like Margaret, felt it was better to plan and be in control as far as possible.

> it made me think if I had a real problem I couldn't rely on anybody up there and perhaps it was time to go before I had to go. I think I like to be in control of my own life, I wanted to chose where I went, I didn't want to be…. and when I told the boys they couldn't believe it. "Oh Mum, we love this little house" and I said "I know you do and so do I but"… and then, afterwards, they said they can see you're right, you don't want a crisis decision, you

> want a decision that you thought out. ... I've sold the house, I've now got some money behind me as well, which is just as well because I don't know who'll look after me when I'm really old and, you know, can't stay here. So, and I don't really……I've paid for my funeral, I did that recently. [Margaret, 83, divorced, sheltered housing on own]

Practical resources

As well as the personal resources we have described above it was clear that the ways in which people adapt to getting older also depended on what practical resources were available. These include things like money and technology, and having opportunities to take part in activities and continue to have a role in society.

Keeping active

Many of the older people in this study wanted to feel involved in wider society, either through volunteering, having interests and hobbies, or belonging to social groups or church communities. Having opportunities to be 'active' and join in were clearly important, although many people commented that this becomes increasingly difficult with age and frailty. What people got out of these activities varied – a sense of connection with others and social interaction; new skills and ongoing learning and development; having a role and feeling valued – all of which could contribute positively to well-being and may counter negative feelings and assumptions about getting older.

> all I can say is that you need to be involved, I think with your friends if you have got any..., family, friends, church life, social life like clubs because there's clubs, not to just sit in the chair … keep the outside world in as well as much as you possibly. [Elsie, 81, widowed, own home on own]

Some people described leisure interests that were not necessarily about social contact. Intellectual and cultural pursuits, such as music and reading also played an important part in their activities:

> Now you're going to think I'm terribly….that I'm a freak or something, because I don't feel that I want or need anybody, I'm a bit of a loner, a lot of a loner, to tell you the truth. I like my own company and I'm always busy, I've always got things to do…oh music, I listen to music all day, without music I can't exist. I adore it. So I listen to it all the time. [Iris, 88, divorced, own home on own]

> I do go to concerts still and now I've moved down here so near it's quite easy to get to [name] and can even go to an evening concert now. It's on the doorstep, so that's nice, and near the library. [Margaret, 83, divorced, sheltered housing on own]

> There are times when I am here alone and I do feel a bit on the lonely side but I get over that, I bang some music on the CD player, that lifts my spirits, I like music a lot both jazz and classical music. [Charles, 79, widowed, own home on own]

Many described how they had learnt new things since retirement. For example, Joan, a retired teacher, was able to use existing skills and knowledge in a new context as a trustee and learn new things at the same time:

> Enormous amounts of things. I was a very late developer and it has taken me an awful long time to learn a hell of a lot of things about myself and people relationships and everything. So I think, you know, I am still learning… so very much learning; well I have learnt an awful lot these last four years [Joan, 74, widowed, own home on own]

Others enjoyed learning about new places through travel and holidays:

> But I think, you know, we try, even now, we try to... go somewhere, you know, where we probably haven't been before and then we see things round there. I think that's something that you've got to do to keep going, you know, and it gives you interest and that's what we do, and we are already thinking about what we might do next year or even, you know, we know that at Christmas time we always go and see our daughter anyway. [Richard, 89, married, own home with wife]

Many people were involved in volunteering which, as well as providing opportunities for learning, also contributed to feeling valued. Some people had been involved in local charities and community groups throughout their life and others had found that voluntary work in retirement enabled them to have a role and a sense of purpose. It also provided opportunities for social contact and having connections to others. Many felt that being able to 'give back' and help others also helped their own sense of self worth:

> I had to face reality ... and after being needed.....I didn't have a job, I didn't have anything to get up for, I was depressed for a while... It was very difficult at the beginning....but once I got involved in the [name of charity] I felt I was part of a team. [Susan, 73, divorced, own home on own]

> I worked at the [charity shop] until I was 92, and of course I miss that terribly... Oh, that was lovely. Meeting people...and I had to give that up because I had problems with the walking.....I loved every moment of it, you know. I sort of got up on Tuesdays and Thursdays thinking 'I've got something worth getting up for'. [Grace, 97, widowed, own home on own]

> Voluntary work is a two way thing ... you give your time, you give your expertise but what you get back is far in excess. [Focus group 2]

> Most people like to feel useful ... and a lot of older people especially if they are alone might feel a bit ... abandoned ...yes you are abandoned you are put on the scrapheap you are past this age and that's it ... so it 's a way of feeling useful. [Focus group 2]

> Doing voluntary work [since retirement] has given me a new lease of life …. When you stop working you tend to drift a bit and for me to have to get up and have to go to work and travel in all weathers and have to put up with difficult people to be told what to do … is very therapeutic … and that makes up for not having a partner … you feel you are not just drifting you are making a contribution. [Focus group 4]

Going to church and belonging to church groups had social dimensions as well as expressing faith:

> I go to church Wednesdays, I've always loved my church, and I like that and Wednesdays are nice because there's a nice smaller crowd of us because all the younger people are at work you see, and that's only half an hour and I look forward to that, I used to go a lot more often of course, so yes, I look forward to that. [Elsie, 81, widowed, own home on own]

> Well on certain weeks in the evening I have particular prayer groups I attend and I really look forward to those. They are monthly but they fall on different weeks usually, so that's marvellous. I really look forward to those immensely. [Kathleen, 67, single, own home on own]

> Well, we do have some extremely interesting services... But, I enjoy, as much as anything, afterwards going into the little room behind and having a cup of tea with the members of the congregation and having a chat, that's nice. [George, 86. Married, own home with wife]

Some people found that joining social groups, such as book clubs, knitting, or yoga, helped them combine maintaining interests and meeting people. Some commented that belonging to a regular group helped provide structure and routine:

> I belong to two groups and one is always on Monday lunchtime at [name] and I go to that because it gives a kick-start to the week. [Pam, 79, widowed, sheltered housing on own]

> It's important when you wake up in the morning, if you are on your own that you have got somewhere to go. [Focus group 1]

> I think it's quite good to a framework to your week ... like you used to have at work ... I think that what people often miss ... one day blends into another ... if you know you've got a group on Tuesday and another group on Wednesday it helps you keep focused. [Focus group 1]

> I think it's important to have a social network which allows you to express your interests and hobbies … joining things like the National Trust, or scrabble, chess things like that … which keeps you active, mentally sharp and you meet people too … I'm a bachelor I don't have a family so without these I would be socially isolated [Focus group 4]

Financial resources

We asked people to describe their financial situation by selecting from one of the following: 'well off', 'comfortable', 'getting by' or 'struggling over basics'. Most people in the study described themselves as either 'comfortable' (17 people) or 'getting by' (11 people), one woman described herself as 'well-off' and one man described himself as 'struggling over basics'. We included these questions because we wanted to know how people talked about money and the ways in which financial resources might impact on well-being.

People talked about a range of financial resources - savings and investments, pensions, benefits (pension credit, housing and council tax benefits), and in one case earnings from part time work. Most people indicated that they managed on their current income (whatever level it was), but for some receiving benefits was crucial in achieving this.

> I have only got my pension and pension credit...money is very important because I have got no bonds, certificates, pensions or anything because I never worked until my husband died and then I didn't pay my pension. [Elsie, 81, widowed, own home on own]

> The local council wrote to me...and they said - according to our records, your income is below what you should have, and we suggest you apply for supplementary benefit –which was something I had never, ever done. And I don't have to pay community charge at all. [Connie, 87, widowed, own home on own]

Financial hardship was also an issue in one of the focus group discussion:

> I find it very hard on my income at the moment with bills and things … unfortunately like everything else you just cut your cloth according to what you've got. [Focus group 5]

> Since I retired and lost my husband things have got dearer and dearer and dearer … you lose money on your savings … the council tax and the water …. Everything has gone up tremendously. [Focus group 5]

There was general agreement that financial resources were important. 'Having enough' without having to worry came up in many people's accounts.

> I never wanted to be rich....but I think it's nice to have enough and its nice not to have to worry....it is important to have enough. [Margaret, 83, divorced, sheltered housing on own]

> I do think it is important people feel that they have got adequate means without having to worry.... I wouldn't want a lot of money, but you need to feel that you have got adequate. [Kathleen, 67, single, own home on own]

> I earn about 10p a week too much to be able to claim benefits.....I don't know why, I just don't come into the category.....so I've only got enough savings to feel secure, if I got down any lower than I've got I would feel very insecure and yes, then my well being would come into play. [Pam, 79, widowed, sheltered housing on own]

As well as wanting to feel secure about having enough for present needs, many described how having enough for the future was also important and could be the cause of worry and anxiety (as we have seen in relation to thinking about the costs of future care needs). Many spoke about the necessity of planning ahead and careful management of what income they have to make sure they can meet their needs:

> We are not well off, that's sure...I think we could say with some sincerity really, we are comfortable... You have to manage it properly. We don't waste things. We choose very carefully and we spend very carefully, and if there are any ways that we can get it, you know, cheaper, we use it, yeah. We don't take charity, we don't have charity things like that but I think we do things sensibly. We don't waste things. [Richard, 89, married, own home with wife]

> Well I suppose it is [money is important] but on the other hand I manage. But then because I don't do anything, as I say I mean I don't buy clothes, I don't want them, so really what I use it on is my maintenance, I know I've got to keep six thousand or just under in the bank isn't it and, but when your maintenance comes in it's very high and I send it off. And my pension I have stopped so much to try and block the gap, I don't have anything to play with but I'm not hard up, I mean I, if I wanted a pair of shoes I expect I could get them but I don't want them you see. [Ethel, 96, widowed, sheltered housing on own]

For some people having enough money was linked to feeling independent, able to be in control and make choices:

> I mean I can only live the way I live because I have got enough money to do it ...I took a vicious hit and all my investments went down....they have come up a bit and it hasn't interfered with my life I'm very , very lucky, I am a lucky boy. [Charles, 79, widowed, own home on own]

For others on limited means unexpected expenses, such as additional service charges on housing, contributed to a feeling of a lack of control as well anxiety:

> And that's why I am having to pay all these big bills.....the council tenants they have had double glazing put in, central heating, all the work's done, these railings are paid for, little

> bit on their rent of course....but we old leaseholders got to pay in one batch. So, it's a big worry. [Elsie, 81, widowed, own home on own]

Many spoke about the necessity of 'managing' on whatever you have and how this was something learned early on in life. This may suggest a different generational attitude towards finance and spending:

> Well when you were brought up to be, you were only brought up to afford the things that you could afford and you were just brought up to be not frugal but prudent ... it was a way of life, wasn't it? .....Dad used to say to us to no, you can't have this, it's too expensive or if you want it you've got to save up for it", and that was it. So we just accepted it and it was just, we never complained. [Violet, 90, married, own home with husband]

> ...all the scrimping and managing I've had to do, it's brilliant you know, you, it really does you good... yes, you've had to...well I can remember...we were paid on a Thursday....And Wednesday night we wouldn't have a bean apart from our bus fare to work. Whatever I get I will manage on.....irrespective of what it is, I will manage on you know. [Rose, 69, married, own home with husband]

Technology

Older people raised a number of issues in relation to technology that illustrate that resources which could potentially make life better are not evenly or similarly experienced. The types of technology people most talked about were mobile phones, using text messages, computers, email, the internet, online banking, and Skype. A few had personal alarm call systems, but no one mentioned telecare or new forms of technology designed specifically for care needs.

Many expressed ambivalence over the increased use of technology and feelings ranged from outright rejection to enthusiastic approval. It was also clear that people felt differently about different types of technology, rejecting some forms and using others selectively.

Some had had difficulties learning how to use computers and mobile phones. These related to the ways in which it is taught as well as the language used and the ways in which manuals are written:

> I do find new technology very difficult. I find that doing things on the computer is very difficult and I find that people don't teach at a slow enough speed. I've had a company come to show me how to do things like attachments and all they do, they do it and I stand behind them and write things down and it doesn't work. And when they have gone I can't do it and I follow the instructions. I'm intelligent. I can write things down, I follow the instructions, the attachment doesn't go. [Jennifer, 76, married, own home with husband]

> My husband is always saying "Take the mobile with you" and I say "No, I forget how to use it" I know, I do not adapt well to modern… I'm very glad we learnt to use the computer at [name] that was very good because they taught you as individuals, you're all there doing things, but you just did your own thing and they came and helped you when you needed help. And I'd have never gone to a class and picked it up, I'm sure, so they were a good learning point I think. But no, I'm not mechanically-minded. [Ruby, 84, married, own home with husband]

> If you are 'untechnical' it would be very nice to have a mentor somewhere around so that if you have a problem with something you could just say show me how to do that. I recently did something and it went wrong and I couldn't get the dam thing out …. And

> I've done a course but you forget if you don't do it enough and I really need a mentor … if you haven't got any children or grandchildren ….If you've got a grandchild that's fine. [Focus group 5]

For some people becoming familiar and using with new technology had been easier because they had been introduced to it either through work or by younger family members:

> I couldn't do without my e-mail and my internet but then I was still working when computers came in and long, many years ago I was trained as a typist, a touch typist …and so when computers came in the keyboard held no fears for me and I was still working at the time and you had to use e-mails so I learned to use e-mail and the web came in a bit later but I do use the web. [Joan, 74, widowed, own home on own]

> when I was at work I was introduced to computers and I was really awful at it ….I got everything wrong… but I taught myself and I….it's gone on from there I use it for practically everything now. [Focus group 5]

> not through voluntary changing of my life as I wished it on myself but the children, again, say they're going to drag me into this century whether I like it or not. So I've got ipods, I've got my digital things which I put my photographs on, I've got the computer. I've not bought any of these, by the way, they've bought all these things for me. [Sally, 67, widowed, own home on own]

Those who had learnt to use emails and Skype in particular, described how this had improved their communication with younger family members and keeping in touch with family and friends living abroad:

> when [grandson] was abroad I heard more from him ... I heard more from him ... than I have since he was a small child, because he could communicate with me. [Margaret, 83, divorced, sheltered housing on own]

> I started using a computer as soon as John Major gave us an allowance to go in to do it and I've always had a computer and it's been marvellous because when my boys are overseas I can get a message to them and a reply within a matter of hours and I wouldn't be without it but I'm now sorting things out because I only want to use it for what I need it for. [Pam, 79, widowed, sheltered housing on own]

> Now we are getting older a bit we don't like the long flights and so on, but we do communicate with him by Skype on the computer and he speaks to us on that and we see him, and speak to him and his family, his wife and family, that way. [Richard, 89, married, own home with wife]

> Yes, I mean this is, this comes back to what we were saying about relationships and contacts and we now, I always was a letter writer, I used to keep in touch with my friends by letter, e-mail is just wonderful, and I think if there was one thing that was taken away from me that I would miss most, probably it would be my e-mail... I can be in touch with people all over the world; we can send each other articles you know and discuss things ... and it is interesting to be in touch with friends, very quickly. [Joan, 74, widowed, own home on own]

Many people were selective in how they used technology and recognised aspects which were useful as well as those they did not like:

> Well I have a mobile phone but I'm really not competent with it. I get, I got my oldest

> boy to put in contact numbers and I can dial any of those up. But that's about all I can do. I can't text, I don't know how to text, I don't want to know how to text. I don't like mobile phones really, deep down, I don't like them. I have a computer and I do like the computer ....It's fantastic, it's fantastic... I have used it for concert tickets, opera tickets, that sort of thing but I still prefer to do it on the telephone because I like the human contact. I send e-mails, people send e-mails to me, I send e-mails back to them. Well yes, I can do that. I look up things, google things and find out things, I use i-player to get programmes which I miss, you know on the television because I'm too idle to put it on or I am listening to music or I am reading a book. Ooh I missed that programme but I can get it on i-player. [Charles, 79, widowed, own home on own]

> Not all of us have computers and not all of us are comfortable with computers. I have a computer but I find it a terrific timewaster. I find it great for use as a typewriter and for e-mails and keeping in touch with friends and family but as for information from it, it is overwhelming. [Jennifer, 76, married, own home with husband]

Others described difficulties with technology, such as technical issues in getting broadband and availability within sheltered housing, as well as lack of information on how to resolve problems when things go wrong. Some people felt that the pace of change can also create a feeling of disconnection: the world is moving on at a fast rate without you and this contributed to a sense of feeling out of touch or left behind. Some felt at a disadvantage and even penalised if they did not keep up to date with changes, particularly as more businesses move to online methods, and in some cases make charges for payments not done online.

> I don't like technology. ... I don't like anything to do with machines and things and I find it, I find certain things quite unfair the fact that you pay more if you choose to pay by cash, things like that you know [Kathleen, 67, single, own home on own]

> ...like going to London tomorrow, we went online and got two tickets for £15.70 well I think it is really unfortunate that people who haven't got a computer can't get that rate - that is really wrong.... like the gas ... I am getting these terrific discounts online, and other people who aren't online can't... [Focus group 6]

> I find it very upsetting that if you want anything like insurance its always cheaper on the computer … and I think lots of older people don't know anything about computers and what are you going to do in the future its getting quite scary … everything is going to be on the computer … what's going to happen to older people who don't have computers [Focus group 5]

Others took a more pragmatic approach and felt that if you did not accept that technology is here and learn how to use it, you would put yourself at a disadvantage:

> I don't want to be learning spreadsheets and data base and I don't even want to order my shopping or things like that. So I do use it and am very glad to have it and I wouldn't be without it and I cannot stand people who brag about not knowing anything about it. I would have never believed it but a friend, and she must be 82 or 3, has started this week to do computer lessons – I can't believe she's done it as she's always thought it was a feather in her cap not to know anything about it… "oh, I don't know anything about it and I don't want to"… and I said well you know it's just like learning another language or even not being about to see the language you've got, you are missing so much by not being able to do it. [Pam, 79, widowed, sheltered housing on own]

Some perceived changes brought about by new technology as a kind of loss: not only of old familiar ways of doing things, such as hand written letters, but also that social contact has becomes less personal and de-humanised:

Yeah, I think perhaps that might be a… of course, the great loss on computers, I think, is writing personal letters, I think that's going to be so sad in the future, but then I think of the records to research, are such a wonderful thing. [Ruby, 84, married, own home with husband]

I much prefer if I draw out money rather than go to an ATM I much prefer to do it person to person because you need the human contact I think and these people who have allowed machines to do the job which people used to do have not done any favours to people. [Charles, 79, widowed, own home on own]

Technology is useful … computers are useful for keeping accounts and things but I don't want to go googling on people I like to interface with the world around me … to have vast amounts of information coming at you through your computer I would find stressful. [Focus group 4]

4.4 Places and environment

In this section we look at what older people in the study said about where they live: the spaces and places of everyday life and how relationships with the environments we inhabit can contribute to, as well as detract from, well-being. People talked about their homes, public spaces, neighbourhoods and what they like and disliked about Brighton and Hove as a place to live. We were interested in exploring well-being in relation not only to physical buildings and the built environment, but also more broadly how people felt about their 'place in the world' as they grow older. The themes discussed in this section are organised under the headings: home and home environment, which includes things like feeling safe where you live, maintaining 'home' and adapting to changes, moving home and decisions about future housing; public space which includes things like transport, facilities, parks and gardens; having a 'place' in the world which explores what people told us about experiences of ageing and wider issues such as the extent to which society recognises and values older people.

Home and home environment

Feeling safe

We have already seen in the section on **People** that relationships with those who live around us can make a difference – positively and negatively – in how people feel about where they live. Many people talked about feeling safe and how this had become more important as they had got older. Feeling that there was someone, like a neighbour who will notice if anything is not quite as it should be, added to people's sense of security:

> I'm not at all worried about being on my own. And they've got keys – my neighbours have got keys… but I know every day that unless they see my bedroom window open, [neighbours] are in here like a shot. So I am not worried about being alone. But I think if one didn't have that, you could be nervous, but I am not nervous of being alone. [Connie, 87, widowed, own home on own]

> I live with my husband….but he's away quite a lot….lots of flats can vary tremendously.… in our block there is three flats around a landing and it just so happens that the other two flats are empty……there's nobody in them, I don't like that….because when he is away.. and I know there is nobody in.. it shows how important it is to know that you have people immediately around you, you know they are there and that they would look after you if anything went wrong. [Focus group 6]

Some like Connie, who were living on their own had developed their own strategies for increasing their sense of security:

> as I'm about to open the front door, I shout up the stairs 'it's alright! I'll take this!' giving the impression that I'm not on my own. Bit daft, but I think if you came to the door and I shouted that you'd think 'this old dear isn't on her own. [Connie, 87, widowed, own home on own]

> I leave my keys there because sometimes I go out without my keys so it is very handy. But then, you know, if they haven't seen anybody around or somebody's worried, they can open the door [Charles, 79, widowed, own home on own]

> I'm with Age Concern with insurance and I'm also with the button I've got…the emergency button…I have that as well but touch wood [knocks] I haven't had to use it. It gives me confidence [Grace, 97, widowed, own home on own]

But not everyone had neighbours who could be called on if was help was needed, or who could act as a key holder for emergencies:

> the person who does my cleaning now, they have got them …. But they are not around the corner … but there is nobody else I could rely on to have my keys and to be that person. Where do you get these people, you know, they have got to be immediately close haven't they? [Kathleen, 67, single, own home on own]

Maintaining 'home'

Many people spoke about the importance of keeping their home in good order and the ways in which they did this, often in the face of increasing difficulty due to mobility or health problems. Keeping things going and having a degree of control over the living environment were recurrent themes:

> I do everything, I do my cooking; my housework I do in bits. Do you know what I do? I'll do a bit then I go and have a sit down. I don't have a home helper, I do everything myself. I don't have anybody in at all... I think you've got to keep up a standard. Because you're getting older doesn't mean that you've got to let yourself go. [Grace, 97, widowed, own home on own]

> I have my daughter who will come over on Wednesday ... and helps me just vacuum because my balance is bad and I can't vacuum, or wash the kitchen, bathroom floor. I go round holding on to this for support, trolley, to dust with one hand and polish, not as it was done once but best I can. [Elsie, 81, widowed, own home on own]

> I had a cleaner and. I felt I should have, you know, that I could do it myself.... so I cancelled it. I don't mind because it gets me, when I'm home it gets me out of the chair and it takes me a long time to hoover or dust or something but I do it because I've got nothing else to do so what does it matter? I feel that, you know, I mean I like to keep my flat nice. [Ethel, 96, widowed, sheltered housing on own]

> As you get older ….there is no way at all I'm going to get up on steps in the middle of the room to change a light bulb … that's where you need an odd job man … it is difficult as you get older and you are on your own to cope with the small … Little things that crop up at home. [Focus group 5]

Managing the maintenance of the home was a source of anxiety for some. This included difficulty in finding trustworthy trades people to carry out repairs and the costs involved in structural work that might be needed now or in the future.

> I have got enormous problems and … I think they take advantage of a woman on their own. I could do with somebody coming in and saying "I'll take over" you know, speak to me to make sure that the work when it is done is correctly done and not leave it … I would like an organisation to exist that would help people like myself who would come in and say well we will supervise this for you. [Kathleen, 67, single, own home on own]

> It wants repairing a lot ... I mean I need new double glazing but I can't afford it cos I have had people call and it's going to cost, well, the bedroom is worse, but he said you have to pay for scaffolding but when it was put in, quite a few years ago, they didn't use scaffolding, they came in through the front door and put the double glazing in. Whether it's a new safety thing I don't know. Well I can't afford it and that's all there is to it. [Elsie, 81, widowed, own home on own]

Concerns about not being able to manage the home and garden were mentioned in relation to decisions to move to a more manageable home:

> one of the reasons I left was the garden was too big and I didn't want to be there on my own and, again, without a car it would have been difficult... So I got a smaller garden here, and I miss it a bit but it was getting a bit much. [Margaret, 83, divorced, sheltered housing on own]

Others were hoping to remain in their current home and make adaptations to accommodate their changing needs, for example due to reduced mobility. But this was not always straightforward and might not feasible due to costs.

> I tell you one other thing too that we are facing now, I don't really know what the answer is really, but bathrooms. You know, our bathroom is quite well equipped but, as you get older it is very difficult to use a bath. They have, the local, you know, people have put in things for [wife], they have put in a board that she can sit on and there's a handle, but it really isn't very good enough and we really need a shower... We are hoping to modify our bathroom with a shower. But the cost of it is enormous. We had a man in looking at it a couple of weeks ago and he was prepared to take out the bath and put in a shower. Just that and it started at seven and a half thousand pounds for that. [Richard, 89, married, own home with wife]

As well as making adaptations, some people also spoke about wider changes in their home environment which impacted on their feelings about where they live. As people move on and neighbours change, some people felt a loss of connection and increased isolation:

> You see people come in, they go in and they shut their doors and that's it. You see a lot of them are still couples and one person on their own is shoved on one side... Then in the middle flat they're a couple...I truly can't remember speaking to them, I see them go out in the car but to actually have a conversation...I can't tell you when. Then there's the other flat in the other corner, that's empty, that's waiting to be let, again the person's bought it and is going to let it. I hate these letting flats...when we moved here there wasn't one letting flat, they were all residents. [Grace, 97, widowed, own home on own]

> …you see, I mean all the ones that were in where I lived, they've all gone. ... I would just like to have a few more friends or a few more people to meet and discuss things, unluckily as I say in my flat now everybody that was there when I went there twenty years ago they've more or less all died. The new people with husbands and all that, they say hello and all that but you don't have anything to do with them. [Ethel, 96, widowed, sheltered housing on own]

Public space

We asked people about Brighton and Hove as a place to live. Older people told us what they liked and disliked about the city and commented on things like buses and public transport, facilities, parks and open spaces, the physical geography and landscape and what these can contribute towards well-being.

Getting about

Many people in our study appreciated local buses and free bus travel. For those with limited mobility or without a car, and who were able to use buses, being able to get to places, with relative ease was important for accessing services and keeping connected.

> And I can still get on a bus. I don't go very far. I'll get off and go down [name] Street or I'll take a bus into Marks and Spencers and once you're in Marks and Spencers it's enough. It's a big place. I can do that, but I don't tire myself any longer than that but I can. And the bus stop is outside the house…it's a 10 minute service – it's wonderful. [Connie, 87, widowed, own home on own]

> So, that's one of the reasons that kept me in Hove because the transport, the bus, although they get very held up with who knows what you know, with traffic and so on, we do have a pretty reliable on the whole bus service which is very important to me. Transport's very important especially as I haven't got a car you see. [Kathleen, 67, single, own home on own]

> But the bus service is super-duper, I can't leave here [current home] because I can't find another bus service that compares with it. Every bus that goes to [name] passes my front door and as they come back they stop out there so you can go anywhere in Brighton from just being here so for transport reasons it's super. [Pam, 79, widowed, sheltered housing on own]

Some people, however, found using buses difficult due to crowding and seating.

> We find it difficult to get down to places even on a bus, it's getting on and off a bus, and we have been shoved on. [Jacob, 96, married, own home with wife]

> I got on the bus at [name] and somebody leapt up, which was very kind of her, from one of those tip-up seats. Now, I can't sit on them, I mean, I tend to fall off them and if I don't fall off them I can't actually get up off them.... … so I had to explain that, I said "I'm sorry but I can't sit .....somebody else". But we were absolutely packed in - it was full of people and a lot of the young people I felt could have been thoughtful enough to go upstairs. [Margaret, 83, divorced, sheltered housing on own]

Although people spoke about using taxis as an alternative to buses, these were generally considered expensive and to be used only occasionally. Ethel describes a trip out to a shopping area that she was determined to do:

> I went to [name], I haven't been for years, the other day, I thought a lovely day, I must, I'll go, so I had a taxi to [name]... so I thought I could do up the hill, go and have a bit of lunch and then there's a taxi rank there but do you know I couldn't, I had one little walk and I sat down, I just couldn't do the walking. Yeah, so it's, I'm willing myself and yet I was so tired. All I kept looking for was seats to sit on, so I went and had a fish meal and went to the taxi rank and got it back, so it was an expensive morning really because I think it cost me about seven or eight pound there you know, and then the same back. [Ethel, 96, widowed, sheltered housing on own]

Some parts of the city are not easily accessible by bus, particularly the seafront which is a popular area for many:

> I love that [the sea] and I would love to do what I used to do and go down by the sea – I adore the sea but can't do it anymore because it's such a long walk, terrifically long walk. I can't think of any bus that would go there either. There isn't one that goes down to the front, promenade .It's a long walk down now. I used to be able to do it every day but I can't do it now. It's a shame that, I'm longing to be by the sea. [Iris, 88, divorced, own home on own]

> I mean I'd love to go down the pier, I think the pier's lovely. I always used to sit on the

> pier, take a book and have a sandwich, sit right at the water, but you see I could get a taxi there but I couldn't get one back because when you come off the pier you've got a long walk to the taxi rank, to there you see. So I can't even go there, you know. [Ethel, 96, widowed, sheltered housing on own]

For Jennifer and her husband who has had a stroke and has dementia, going to the seafront is something they can enjoy doing together. But this is because she is able to drive and park nearby:

> We are very fortunate in that we have a blue badge, that's absolutely a godsend and you can park anywhere, you know. And we would be lost without it. He [husband] can walk, he can walk a little way, he can walk, he can get on a bus if I help him but the seafront isn't on the bus routes so we need a car. [Jennifer, 76, married, own home with husband]

Some people described avoiding some areas of the city, due to difficulties in negotiating the crowds, or at night time:

> I feel, because I'm not so mobile now and it's so full, you feel as though you want a pedestrian crossing just to get across the pavement, never mind the road and I shall be quite glad when they all go home from their holidays... it's so crowded and you feel a bit hassled. [Margaret, 83, divorced, sheltered housing on own]

> I just, I would not go into Brighton ... probably more so because I am a nervous person and I do suffer from panic attacks, anxiety attacks and anything like that a crowd, they cause me far more anxiety. Probably because of loss of my vision, cos they get in my way and I think, ooh, cos they rush past you. [Elsie, 81, widowed, own home on own]

> I don't go out at night, I've only ever been really….I mean I go out with the children, they'll take me out for a meal when they can, or if I'm meeting my friend, but funnily enough when we went out the last time I came home on the bus and the children went absolutely mad at me, I was to take a taxi home when it was late, in the evening time I was not to go on the bus. [Sally, 67, widowed, own home on own]

> Well that limits your social life somewhat, even though you've got a good bus service, you don't really want to be walking around the streets at 10 or 11 at night, I don't know why I don't, but I don't….so there's…hours after five, life after five is non-existent, let's face it.[Pam, 79, widowed, sheltered housing on own]

These issues were also reflected in focus group discussions. Many referred to reluctance to go out at night which restricted things such as concerts or going to the cinema. Some appreciated day time film screenings aimed at older people at a lower price.

> A lot of women don't want to go out in the evening ... music and comedy things are usually in the evenings. [Focus group 1]

> sometimes I feel if you are ever in the centre of Brighton on a Saturday ...it seems all sort of young people...it's best not to go out. Saturday night at the centre of Brighton it's really not very pleasant. [Focus group 6]

> if you go to the Theatre Royal and have to get a bus to get back ...it's not very pleasant.... well in fact what we actually tend to do we actually walk back home because the busses are so nasty...we can walk back, but when we get older and aren't able to walk back we'll have to pay for a taxi because the buses are so nasty on a Saturday night. [Focus group 6]

Nature and environment

Some of the difficulties in getting around the city can be attributed to the physical landscape with its steep hills. This creates difficulty in accessing many areas of the city, particularly for those with mobility problems:

> It's a lovely area, but not for me now that hill you see. If it was on the flat, if I'd have been in Eastbourne or somewhere like that when this happened [fell and broke pelvis] I would have bought myself one of those motor things, but I did buy one second-hand and then it scared me because I thought if I was down [at the bottom of hill] it stopped and how am I going to get home? [Ethel, 96, widowed, sheltered housing on own]

But one advantage of the hilly landscape is the views it offers which are important to some:

> We can, from here, from the upstairs of this house, we can see the sea, we can see the palace pier and the sea....[the hills] are an awful nuisance for us when we are older, but the views and the pleasure they give. I think probably this is why we like this house so much. [Richard, 89, married, own home with wife]

> There comes a time we can't climb 42 stairs and then our plan would be to live somewhere else at [name] that didn't have so many stairs, but with a view, because what gives me a great sense of joy, of happiness, is a view. A view is really, really, it is important for my soul...And it does help when it is a sunny day because it raises my spirits. It gives me a greater sense of well-being. [Jennifer, 76, married, own home with husband]

As we have noted, the sea and seafront are popular places. The ways in which people spoke about these and other public places, like parks and gardens, show how having access to outdoor space can positively contribute to well-being:

> So what I did was, opened the door, because the sun comes right through here... what I normally do is take a chair which I have got there, sit it out there ....and just, well, sit and relax and I think oh this is beautiful, this is lovely. I can see the sea, I can see people walking along, makes me a bit sad thinking I used to walk along. [Elsie, 81, widowed, own home on own]

> Well I think the, I think the seafront and the sea are very important to me and the lovely gardens, you know, those sorts of things, now all the daffodils are coming too and it is very beautiful. Yes and of course the promenade we are very fortunate we have a lovely promenade which I love and I can see the sea from where I live you see. I just adore the sea. Yes, it is lovely to see the sea [Kathleen, 67, single, own home on own]

Facilities

We asked interviewees about local facilities and amenities. Some described Brighton and Hove as a lively place and enjoyed the cultural life it offers.

> There's a lot going on in my opinion in Brighton. I only came here about 20-odd years ago and I think there's a lot... I think there's a lot of free stuff going on, isn't there? there's always something. [Margaret, 83, divorced, sheltered housing on own]

> I love it if I can get to a good play, I love the theatre. Recently they haven't had very much that's brilliant but until about the last month they had some very, very good plays on, we are very fortunate with the Theatre Royal here. [Kathleen, 67, single, own home on own]

> I also like, I like cinema ... I do go to concerts still and now I've moved down here so near it's quite easy to get to the Dome and can even go to an evening concert now. It's on the doorstep, so that's nice, and near the library. [Margaret, 83, divorced, sheltered housing on own]

Others suggested that being able to go out and enjoy public spaces and facilities as an older person also depended on practical considerations, such as availability of public toilets and seating:

> there are some local authorities that have made deals with pubs and shops and they pay a publican or a shopkeeper so much money and they put a notice in their door to say this is a public toilet, yeah. That's a good thing. We haven't got that in Brighton and we should have it. [Charles, 79, widowed, own home on own]

> It's not good for seats between the pier and the Marina. You are lucky to find seats except in the wrought iron part under the road. Actually on the seafront there are very few seats and in Brighton itself, there are few benches. I wish there were more and I wish there were more public loos. [Jennifer, 76, married, own home with husband]

Having a 'place' in the world

During the interviews we asked if well-being had changed over time and this invited reflections on growing older and what interviewees felt about being an older person. As we have already seen, being able to draw on a lifetime of experiences and learning to adapt to changes can help sustain well-being. But what also came out of these reflections were ways in which older people felt that their place in the world was less secure than it had been. This related to the extent to which they felt their needs were recognised and acknowledged, and links to many of the issues that have been raised in this section on public space. We include here some reflections of the interviewees on how these issues play out on an everyday level, in the ways other people treat them and how they see themselves as older people.

Ruby reflected that when she was younger she hadn't understood or thought about how an older person with hearing impairment might become marginalised. She has realised what this can mean through her own loss of hearing as she has got older:

> it's taught me quite a lot about getting older but one could have been more patient and kinder to old people, be a little more conscious of them, perhaps. When you're young, you rush around and you're busy. I've been with old people and I always give them time, but thinking back more on… my mother was deaf and sometimes she'd be with us in a group situation, one could have been more conscious that she wasn't taking part because she couldn't hear and become frustrated, particularly if it was a group of one's own friends that she didn't know, that sort of thing… so it's too late to think back and think 'oh, I could have been nicer over that' or 'I could have…' you learn in life, don't you? [Ruby, 84, married, own home with husband]

Some participants described examples that indicate that how people feel about ageing is not only related to self perceptions, but wider societal attitudes towards ageing and older people.

> I don't know whether it's because I'm in this house or I don't know why it's suddenly arrived or whether it's to do with age. ...I talked to my friend and she says she feels it as well, you seem to lose control in some respects and also you become, when you're a widow, you become sort of a non-person, I don't know how to explain it … We always call it sitting in the back seat of the car and you've got a couple sitting in the front seat of the car and you're sitting in the back seat of the car and they're having a conversation and they do include you every so often but you're not part of it, and that is a sense….

> it's not a nice feeling... [feeling you are] not important. [Sally, 67, widowed, own home on own]
>
> And I'm not being funny or, but unless you've got family and even that they wouldn't always help... But if you just had someone to phone and talk to and discuss things ... and say "what do you think?" And you must expect these things at that age but as I say I wish they'd have given me a tablet and put me to sleep which would be fairer, and to everyone really because I'm no use to anyone. [Ethel, 96, widowed, sheltered housing on own]
>
> I think....oh, without a doubt. I think the elderly people now are treated as a nuisance. We're all living too long for them, the young people are just thinking about, you know, 'what are they gonna leave us?' [Grace, 97, widowed, own home on own]

In section 6 we discuss ways in which it is not only age that can affect people's experiences of continuing to have a place in the world. Unfortunately we cannot say much about the experiences of older people from different ethnic groups in this respect, although we do have some indication from the BME focus group that lack of cultural awareness about food and other issues can impact on feelings about care services and the extent to which these recognise the diversity of older people.

Conclusion

Whilst many people enjoy their lives post retirement, for some it can be hard to sustain a sense of well-being in old age. They may be dealing with losses: of friends, family, health, and the identity and structure offered by work. Some may find it hard to adjust to personal changes and to changes in the world around them that make them feel out of kilter with social life. What is clear from our research is the importance of different types of relationships to older people's well-being. The quality of relationships not only with family and friends, and with health and social care providers, but encounters with GP receptionists, people at the bus stop or at check out counters in shops, can make a difference to how people feel about themselves, because they indicate how others feel about them. People's relationships with the spaces and places in which they live also make a difference, as do practical things like feeling you have enough money to cover unexpected as well as expected costs. New technologies can be both a means of keeping in touch when physical activity and travel become problematic, and a source of frustration if it is assumed that everyone feels comfortable with using ICT. Well-being is a complex aspect of the way people feel about their lives in relation to the world around them. It is not something that they can achieve for themselves alone, but something that is affected by the way others treat them. In the next section we consider how these different factors interact in the lives of selected older people involved in this study.

5. Narrative Analysis

The thematic analysis has highlighted key issues identified by older people that are significant in affecting their sense of being well in the world. But the limitations of this sort of analysis are that it isolates specific topics from the social and biographical context of older people's lives. In order to build a greater understanding of how issues such as people's experiences of poor health – their own or that of close relatives; their feelings about Brighton as a place to live; or their responses to the social changes taking place around them interact in the context of their lived lives, we selected seven interviews to undertake a narrative analysis looking at the interview as a whole. We selected these seven interviews to include people of different ages, women and men, living in circumstances that might be considered objectively to be both 'comfortable' and more difficult. In this section we consider the nature of the stories that run through these interviews and how this can help us understand better the way in which different factors interact to affect well-being.

We start with brief descriptions of the circumstances of the 7 people whose interviews we analysed in this way. We have already met them in previous sections, but here we are able to place what they have been saying in a more detailed context.

Elsie is an 81 year old woman who is widowed and lives on her own in her own home which she used to rent from the council. She described her financial circumstances as 'getting by'. She had a stroke a year before the interview and this has affected her sight and her legs. She has four sons, 15 grandchildren and 5 great grandchildren.

Grace was 97 at the time of the interview and lives alone in a flat that she owns. She described her financial situation as 'getting by' and said she was disabled as she had difficulty walking. She is widowed.

Peter is a gay man who has been HIV positive for over 20 years. He was 74 at the time of interview, single and lived alone in a flat rented from a housing association. He described his financial circumstances as 'comfortable'.

Mary (75) spent most of her life living in residential homes without contact with her birth parents or siblings. She has a learning disability, has difficulty walking and is suffering from hearing loss. At the time of interview she was living with a family to whom she was unrelated. She described her financial situation as comfortable.

George is 85, married and lives in his own home with his wife. He described himself as comfortable and as not having a disability although he did have cancer.

Jennifer (76) lives with her husband who has had a stroke. She identified herself as a 24 hour a day carer. They lived together in a flat that they had bought with proceeds of the sale of their large house after his stroke. She described their financial situation as well-off/comfortable. They have a daughter and grandchildren living abroad.

Eddie is also a carer, in this instance for his wife who has had mental health problems for much of their marriage. He is 85 and retired early to look after her. They live in council rented accommodation and he described their financial situation as 'getting by'. He has cancer and diabetes.

All these seven people described themselves as white British or English.

The current circumstances as well as personal identities of these seven people highlight the diversity of older people's lives. The stories they tell reflect different histories as well as current circumstances, but what is common is what is particularly distinctive about old age – that their sense of well-being, or its lack, is tied up with the way in which their own lives have changed over time and, to some extent, the way in which the world and thus their relationship to it has also changed. Thus we start with narratives of change.

Being Well through Change and Loss

Inviting older people to reflect on what well-being meant to them and the circumstances in which they experienced this, resulted in different narratives that emphasised both loss and disruption, and adaptability and resilience. Thus Jennifer's interview introduced the significance of loss very early on as she spoke about the impact of her husband's stroke on both him and their life together. This theme continued throughout the interview. For him the stroke meant loss of memory, increasing confusion and a tendency to fall. This, in turn, meant increasing restrictions in the activities he was able to undertake. It had led to a decision to sell the big house they used to own and to move into a flat and 'he absolutely hated the loss of a garden.' Jennifer described the house itself as a loss, but one she recognised was part of other life changes as it had become too big for the two of them and too hard to look after. But her husband's stroke had impacted in other ways: on loss of friends because they wanted you 'to be the person you used to be'; on their enjoyment of Brighton as a place to live because the 'busyness' of the place caused them to avoid it; on her health and the ability to make choices that make life more exciting and fulfilling; and on what can be considered the loss of her female role within their relationship as she had to take on what she referred to as 'the traditional male' role in dealing with finances, car maintenance etc.

But intertwined with this narrative of loss was another narrative: that of adaptation and what Jennifer referred to as 'getting through.' This referred to her strength and capacity to adapt, develop new skills and recognise what sources of well-being were available to both her and her husband. The strategies she tried did not always work – thus she proposed they should buy a small house that they could renovate as he had enjoyed DIY. This did not work out as his condition deteriorated too fast for it to be possible for him to work on it. Jennifer explored what activities continued to be possible for them to enjoy together: including visiting a photography exhibition on the seafront and then having a picnic, and meeting up with friends where one partner had also had a stroke. She made sure she continued to go dancing regularly which was an activity she loved, and planned activities for her husband that would give her a break. Living close to the sea was important for both of them, so when they sold their house they had bought a flat near the sea with a view. Jennifer was anticipating they would need to move again when managing the stairs became too difficult and they would stay close to where they are now: 'a view is really, really important for my soul.' Jennifer had also adapted both to the changing gender relationships within her marriage and to becoming a carer. Thus although she did not enjoy dealing with finances, the car and garden, and said she almost lost her mind over these things, she also spoke with some pride about her capacity to manage them. And she had not only sought all the information she needed to ensure her husband received the services he needed, she challenged professional judgement about his condition and had become a spokeswoman for other carers.

George's change narrative emphasized a lifetime sense of having been fortunate as well as a positive adaptation to growing older. He frequently referred to himself as having been 'lucky' during his interview, including having survived the war when others didn't, having recovered well from prostate cancer from which his brother died, and having adapted to changing personal circumstances following problems with his business during the Thatcher government. He accounted for his ability to adapt to change by having been sent to boarding school and learning to 'rough it, rather', and to having developed a calm, philosophical view of life.

For Elsie adaptability was forged through difficult experience. She experienced the loss of her mother in childhood and then of being harshly treated by the family with which she was billeted when she was evacuated during the war. She talked of wanting to die after experiencing abuse, but then gaining the courage to run away. She married young and was then left with two young children after her husband left her. She remarried and her second husband died suddenly when he was 47 leaving her with four children. In her current circumstances she had needed to draw on the strength and determination she had developed to build up the confidence to go out after her stroke had badly affected her walking – she had a fall in the road that had left her terrified. She

had been helped in overcoming her fear by support from volunteers. Ensuring continuity through maintaining her links with the church and her family is also important to her.

Particular changes have particular significance that relate to aspects of personal and social identity. For Peter, changing legal and attitudinal perspectives on homosexuality that made coming out easier, interact with what he identified as ageism within the gay community. For Mary, changes in the way in which people with learning disabilities are treated generally are reinforced by a sense that she now has a family to whom she can relate.

For others, the changes they identify are very personal. Grace contrasts her account of her 'successful' life – ballroom dancing and wine making, being a skilled craftswoman, an air raid warden in the war and with a husband in the Guards and the police: 'they were lovely days, I've got a lot to thank for', with her current circumstances in which her ability to do things is impacted by loss of mobility and a sense of having outlived her usefulness. Perhaps in contrast, Eddie's story offers a sense of continuity of personal struggle to sustain a sense of well-being in the context of having needed to care for his wife since she developed post natal depression.

Losses associated with physical capacity can mean loss of valued activities – Grace spoke sadly of having to give up her work in a charity shop when she was 92 because she could no longer walk there. And for people like Grace in old, old age the loss of people who have been very important to them is something that cannot be replaced: 'It seems as though I've lost everybody who's been close.' In this context the importance to well-being of finding opportunities in the here and now to make people feel valued becomes particularly important (see below). Grace talked about the way in which she has had to adjust and cope – anticipating the impact of first her husband no longer being able to drive, and then of becoming isolated, by moving from a house with a garden on a hill, to a flat on the level and by a bus stop; by having a bath taken out and replaced with a walk in shower so that she could have her daily shower and not 'let herself go.' This highlights the hard work associated with maintaining the practical circumstances that might be capable of sustaining things that are important to people's sense of well-being. But this work of adaptation is not only practical – it also involves a substantial amount of emotional labour. Grace does not experience her relationship with her son as supportive of her well-being. Because of this she seeks to remain fiercely independent: 'I never ask the family to do anything, not a thing', but at the same time 'my heart's breaking but I mean I've cried all the tears but then I sit down and I think "pull yourself together there's nothing you can do about it, just take it as it comes"'.

The convention of narrative is that it moves from past to present to future in a linear way. The stories told here did not all conform to this chronological structure and the interviews were not conducted in a way that invited this. But most offered an account of well-being that highlights the significance of being able to make sense of life changes over time and thus the need to understand well-being not as a steady state, but as a dynamic process of responding, adapting and negotiating. These accounts are personal accounts, reflecting individual and shared biographies and the way in which these contributed to current experiences of being well (or not). But they also highlight the importance of changing cultural and social norms and the way in which these impact on subjective well-being (eg attitudes towards gay men and people with learning disabilities); they indicate the way in which material circumstances can make it easier to mitigate losses (eg being confident that it will be possible to retain a home that is not only comfortable but enables contacts with the kind of physical environment that is a source of well-being) , and they indicate the significance of particular historical moments and events in providing a benchmark against which to assess current circumstances and experiences (for this generation of older people, their war experiences are often significant).

Caring, being cared for and other relationships

Our thematic analysis has already highlighted the significance of different types of relationship to older people's well-being. Here we consider what this narrative analysis contributes to an understanding of the relational dimension of well-being during the course of people's lives, but also the different types of relational narratives that are evident. We start with the two people who identified themselves as carers and for whom the experience of giving care to their spouse is central to understanding both what contributes to and what detracts from their sense of well-being.

Eddie's interview was entirely constructed around his story of caring for his wife who developed post natal depression in 1964 after the birth of their child. His life since their marriage has been shaped by responding to her needs, by the time she has spent in hospital and her subsequent move into a care home. Her frequent admissions to hospital impacted on his work and eventually he was offered early retirement and took this with some relief to concentrate on caring for his wife. He was dissatisfied with the way she was treated when she moved into a home for older people with mental illness, and he complained about this both to the manager and to service commissioners and inspectors. For Eddie, securing good care for his wife was fundamental to his own well-being. When he was told that it would be detrimental to her health to move from the home she was in,he described his sense of being 'on my own, I didn't know what to do', indicating his need for support to ensure he was able to be well in very difficult circumstances. When he was able to secure a move to another home where the care she received was much better, this provided a much greater sense of personal well-being: 'I feel very happy with myself and I get on alright, I get out, I take time off…' This is in spite of being able to have very little conversation with his wife and of the fact the he has developed health problems of his own. Eddie has also learnt about the need to care for himself and his greater security in the care given to his wife has meant he can focus both on addressing his own health problems (sorting out a Macmillan nurse) and even taking a short holiday.

The majority of Jennifer's interview was also constructed around the impact that her husband's stroke has had on their lives together. As we have seen, much of that is concerned with loss and the need to adapt to changing circumstances and expectations. She sums up her personal position as 'my life is really as a carer for someone who needs a lot of care.' Her narrative highlights the organizational demands associated with caring – making hospital appointments, organising sitters, sorting out attendance at day care, exploring the availability and cost of respite. She does not talk much about hands on personal care. But she also talks about the way in which she has become a 'voice for carers' and this discussion of the way in which she takes on professionals – both on her own and her husband's behalf, and on behalf of other carers - suggests that she has also found a new role that offers recognition of her abilities. This more public identification as a carer is not there in Eddie's narrative which rather concentrates on the personal struggle in which he was engaged to secure good care for his wife.

Jennifer is explicit about the need to care for herself as well as her husband. Thus she has organised sitters to enable her to continue to go to dance classes that she loves, and to enable her to attend hospital appointments for herself. Her story feels rather more personal when she talks about her relationship with her daughter and her grandchildren and this also demonstrates the impact that different caring relationships can have on each other. Her daughter lives abroad and has had her own difficulties with marriage breakdowns. Jennifer rarely sees her daughter and struggles to offer support. When her (teenage) grandchildren visit it is 'disruptive of the care regime' that she has established and it creates additional care demands from young people who assume that grandmother will look after them, shop, cook, wash their clothes and make sure they're warm enough. This suggests that the balance that Jennifer has established in terms of ensuring her husband is looked after, and that she is able to look after herself, becomes disrupted when non-reciprocal care demands are made that place her firmly in a gendered 'mother' role.

This disruption undermines both the practical organization that she has established, and the adjustment she has made to her role. This threatens her sense of well-being.

The significance of care to well-being is not restricted to relationships identified as caring relationships. Grace contrasted the way in which her son offers a functional service to take her shopping with the way in which similar help is provided by a friend's son who makes her feel 'just like the queen' by making a shopping trip into a special outing. 'You know he says 'don't you dare open the car, I'll do that!" Opens the car, gets the… I say 'darling, I can put my seatbelt on, I'm not helpless' and he says 'you'll do as you're told when you're out with me.' And he treats… it's just wonderful, he's such a darling.' Much official discourse of well-being associates this with independence. As we have seen Grace seeks to be independent, but this is not because she values independence in its own right, rather that she has learnt not to expect help from her family. She described her response to this in answer to a suggestion from the interviewer that she liked to make her own decisions: "Well, no I don't mind that. They can tell me what to do, it's just that I don't like asking. I just feel that I'm being a nuisance – that's the word – and I don't want to impose. Because I'm old, I don't want them to think that I'm… you know? So I mean I never ask the family to do anything, not a thing." Her well-being is undermined by the lack of awareness from her son and his wife that she needs – and wants - to be cared for.

Peter's narrative highlighted the importance of relationships to well-being in different ways. Early on in his interview he talked about having worked as a personnel manger and how he dislikes the term 'human resource management' that came to replace this term. This was the start of a narrative that emphasised the significance of human interaction, face to face contact and friendship. Friendships have been important throughout his life, enabling him to enjoy activities such as visiting the theatre and going out for meals. Friends are also people with whom he can share experiences of medication. His capacity to retain face to face contact is limited by the fact that he gets tired and can no longer travel as he used to, but he likes writing letters and was scathing about Twitter as a means of keeping contact. He has lost friends to AIDS, but friends also help him out with looking after his flat.

Peter's narrative of friendship reflected not only the personal significance of friends to his well-being, but also his experience of being a gay man and part of the gay community. He thought he made friends easily, but being gay can be experienced as a barrier to uncomplicated contacts with 'strangers.' He spoke of the mining community in which he was brought up and the friendliness of this, but also that 'if someone actually appeared at a club and all dressed up in drag or something like that…everyone will know.' At the same time he identified ageism within the gay community, linking this to an emphasis on hedonism. Nevertheless he feels a commitment to the community and to supporting those within it – both old and young. He likes to encourage young friends who are not familiar with the theatre to get to know this and to share his love of this; and he spoke of a wish 'if I won the lottery' that he could buy a big house and let it out to gay older men, particularly those with HIV, who are in need of support. Thus he demonstrates a sense of wanting to reciprocate for the support he feels he has received and that has contributed to his well-being.

In George's case 'helping others' was an enduring theme throughout his life that has been expressed through different types of volunteering at different times. He currently reads to people and offers conversation and companionship to residents in a hostel and recognizes that this offers personal benefit to himself: 'I enjoy doing things or seeing that they are pleased or happy, you know, they like it. If I found they didn't like it then I wouldn't be happy at all.' His sense of his personal good fortune is highlighted by the comparison with the position of those he seeks to help. Gaining recognition and a positive response from such people is important to him, and a suggestion that they do not appreciate his input is something he finds hard: ''Some seemed happy and pleased that you were doing it and others, well they were rude and thankless really and you felt is it really worth dealing with these people".

We have already indicated some aspects of family relationships that affect older people's sense of

well-being. George thought his family was unusually blessed in being close and supportive. Elsie's narrative more directly emphasised the importance of reciprocity and sticking together to deal with difficult circumstances. Each member of the family has particular problems to contend with: Elsie has had a stroke, one of her sons became a single parent, another was made redundant, whilst another is insecure in his work. One of her daughters in law suffers from diabetes and has difficulties with her legs as a result. These problems were described as what life is about and sticking together and helping each other out is how they cope. Elsie's description suggested that, in spite of her stroke and her lack of confidence arising from the impact of this, she retains her position as 'the mother' and head of the family. Thus although she worries about her sons, her capacity to care for others remains important for her.

For Mary, 'finding' a family in older age has been the source of well-being. She spent most of her life in residential homes without contact with her birth parents or siblings. She hadn't sought them out, but noted 'it's nice to know you've got somebody out there that you might meet one day.' Now that she is no longer being 'pushed around from home to home' but is living in a foster family, she feels settled and happy. She spoke about going on outings and celebrating birthdays and of how the children come up to her and cuddle her and tell her they love her. She is learning about living with others in a family, recognising there are times when people need their own space, how it is possible to upset the people you live with, but then make it right again.

Eddie's care for his wife affected his relationship with others – including their daughter who was brought up by Eddie's step mother and who said he should have left his wife. They have little contact now. The poor care his wife received in the first home to which she was admitted had led to a mistrust of others, though this had been relieved by a more positive experience of the home in which she now lives and a sense that he could build a relationship with the staff who work there.

Once again these narratives of relationships and care are both highly personal and reflect important social and cultural influences on well-being. Care is vital to well-being, but can be a highly ambivalent experience for both care givers and receivers. This, in turn, is affected by the extent to which care is supported and valued, again both personally and socially. Well-being narratives all address the issue of family – but not solely in terms of the positive contribution of family to well-being and not only with an understanding of family as kin. For both Peter and Mary 'family' is found rather than given. Peter has a sense of himself in relation to a community of identity, whilst George seeks out others to offer support and from whom he can gain recognition. These different narratives of relationships reinforce the way in which it is not possible to understand well-being as an individual state, but why we must understand how it can be produced in and through relationships.

Recognition, respect, and identity

Relationships of another kind are also implicated in a third narrative that characterized accounts of well-being and how it is produced. Mary was the most explicit about the importance of being respected and treated properly, perhaps because she had to 'stick up for my rights' throughout her life. For example, she said she had been badly treated in the home she used to live in – she wasn't allowed to do her washing when she wanted to and she had been passed over for a downstairs room that she had wanted. Although there had been physical improvements in this home she was glad to have left because of the way she was treated there: 'it's just the way people treat you, you know, you don't get treated with respect, you get treated like a bit of dirt off the carpet.' She also spoke of having money stolen from her when she went to the toilet at a Bingo hall: 'I thought that was disgusting. I never got over that.' When asked what service providers could do to ensure older people's well-being her reply was 'treat 'em better.'

Mary's experiences of disrespect are embedded in being seen to have an identity as a 'stupid person…. Mentally handicapped' and in her old age she at last finds recognition for herself as a person through her move to live with a family. This is associated with changes in the way people

with learning disabilities generally are treated. Thus her well-being has improved as she has grown older. For others it is old age and the way that this is perceived that brings about a loss of recognition or respect. This is particularly notable in Grace's narrative. We have noted that she is no longer able to do things she enjoyed (such as working in a charity shop), and that this is a loss to her. But in addition to the loss of activity this has contributed to a feeling of having outlived her usefulness. The prime cause of this is the very limited contact she has with her son and daughter-in-law and the way they treat her when she does see them. She does not see them very often and they rarely phone her. She says she does not understand their behaviour towards her: 'I always say if you've had words, sit down and talk it through. But we've never had any words, it's just as though I don't exist'. Her son had taken her to visit a private retirement estate where they planned to move – but only after she had 'passed on'; it was unclear whether this was because they were waiting for an inheritance. She appears to have internalised a sense that she is no longer worth 'bothering with' as she reported that she had told her doctor not to review her medication 'throw it all away, whatever it is I'll keep what I've got. I said 'at my age the health service have got enough with young people."

Peter's interview offered a rather different perspective on the issue of personal identity. In a narrative that developed and became more obvious in the later stages of his interview, Peter demonstrated the importance to his sense of well-being of being responsible and being in control of what was happening to him. He was concerned to ensure that his HIV did not rule his life and one way he sought to ensure this was by making sure he took his medication and did not do 'anything stupid.' He had made funeral plans and had investigated if it was possible to leave his body to research to contribute to learning how people can live a long time with HIV. He was concerned that one impact of his health problems was to affect both his speech and his writing. He worried that people would think he was drunk because he slurred and could not control his writing. He spoke at some length about his dissatisfaction with the lack of information from the health service and their inability to understand that giving him an appointment for 7.30 am was not possible because he simply could not get himself up and to the hospital by then. 'I like to know and be responsible for my own life,' he said. He would not seek help in his flat from the council because they have so many rules about what can and can't be done, so he preferred to make arrangements with his friends to help him with this. At the same time he describes a friend as talking of him as 'the most que sera person I know', and said he had deliberately cultivated an attitude of not worrying about things that are out of his control – such as his flat being badly damaged as a result of actions by a neighbour. Perhaps because of his need to be in control of his body and his health, it has been necessary for him to deliberately adopt this attitude to sustain his sense of personal well-being when things happen that are not within his control. He did express concern about what would happen when be became more infirm and his capacity to control these things would be reduced. His own need to be responsible interacts with his sense that the rules of service providers would mean he could not get things done as he needs and wants.

It is perhaps significant that the people who spoke most explicitly about the importance of recognition are those whose identities may have been most threatened by others' attitudes towards them. There was much less in other narratives in relation to these issues, although George's interview highlighted the importance to his well-being of his spiritual and intellectual life. His narrative of his spiritual quest spoke of trying to reflect on and evaluate what different schools of thought and different religious denominations had to offer him. He also described a similar search for a political 'home'.

6. Discussion: Learning to be 'Well Enough' in Old Age

How do we make sense of the very rich data that we have generated in this project? Our analysis has revealed the very different experiences that constitute old age and the varied factors that affect well-being at this stage of life. We know that relationships of different types are important and we know that the resources and capacities that people have to adapt to personal and social changes can make a big difference to people's sense of being well in old age. We know that security, feeling like you 'belong', and being confident that help is there if you need it are all important. In this section we offer a rather different perspective on what these findings as a whole suggest about being well in old age and how this might be promoted. In discussing our findings we use the term 'well enough', borrowing from an article by Taylor (2011) who argues that much of the policy and practice focussed on well being assume a 'high bar' for being well. He suggests that, rather than assuming there is some type of 'standard' to be reached to achieve well being, we should think instead of the different ways in which people try to maximise well-being in situations that may be far from ideal. There is a danger that definitions that emphasise physical health, people's capacity to plan and set goals, and to be active within their communities, may exclude from any hope of being well those people for whom old age is accompanied by illness, a reduction in their physical horizons because of mobility problems and who, because of advanced old age, are focused on being well in the present rather than planning for the future.

The context for this is the fact that more people are living for longer than ever before in the history of the human race. In the UK in 1984, there were around 660,000 people aged 85 and over. By 2009 there were 1.4 million – more than double the 1984 figure, and by 2034 the number of people aged 85 and over is expected to reach 3.5 million - 5 per cent of the total population. Life expectancy is increasing and the number of people living to 100 years or more in the UK more than quadrupled from 2,600 in 1981 to 11,600 in 2009. By 2033 it is estimated that there will be almost 80,000 people aged 100 or over (http://www.statistics.gov.uk). This success story has created a new situation, one in which individuals need to learn what it is like to live to an age that their parents and certainly their grandparents would neither have experienced nor expected, and one in which, collectively, we all need to learn how to live together in multi-generational families, communities and societies.

One consequence of our decision to include people from the age of 65 upwards in this study was that we have been able to consider how people respond and adapt to growing older over a period of 30 years or more, from a point where they might be officially described as 'old' to a point where they are nearing the landmark of 100 years. Interviews with Age Concern staff conducted in Phase 1 of this study emphasized the very different experiences and responses of those in the 'older old' age group compared with those in early old age. The stories that people told of their personal experiences of growing older has led us to reflect on the 'work' that ageing entails, and the learning that is necessary to be well enough at different stages of old age. These are processes that require change and adaptation over a period that may be longer than that from birth to adulthood. Both the work and the learning that is required need to be done not only by older people themselves but by us all if the ageing of the population is be experienced collectively as a positive development, rather than a 'problem' to be managed. In this section we consider what this involves.

One broad conclusion from our work is that we need to understand well-being within the particular and varied contexts of people's lives. We should not suggest that it is inappropriate or irrelevant to think about what well-being means when people are having to cope with illness (their own or that of someone they care for), or with the consequences of the loss of loved ones, or of their own physical capacities. But how we think about this and what needs to be done to be well enough in these situations cannot ignore the way in which such circumstances may challenge earlier

strategies that people have developed to ensure their well-being. The interviews we conducted and discussions amongst team members illustrate the way in which older people need to negotiate a wide range of factors in their own lives, and in terms of changes in the world around them, in order to find ways of maximizing well-being in circumstances that change and can be objectively quite difficult.

Older people learning to be 'well enough'

For older people themselves learning to be well enough involves both emotional and organizational labour during the processes of personal, interpersonal and social changes that accompany ageing. The transitions that people go through at this stage of their lives can be as significant as those involved in making the transition from childhood to adolescence to early adulthood. They involve not only physical changes, but also changes in roles and expectations, in the way people are viewed by others, and changes amongst those other people who constitute sources of companionship, friendship and love.

If we consider the emotional labour involved in being well enough in these we can suggest that this involves (at least):

- Reflections on oneself, what is important in terms of values, relationships and priorities, and how it may be necessary to re-focus or adapt in terms of one's own behaviour and/or expectations of others.
- Learning how to ask for help and to receive care and help without feeling that this means you are a burden, or of lesser value as a result. Recognising that you can also give something to the person who is helping you by the way in which you receive their help and support. Giving and receiving are closely interlinked experiences and can both be present for both giver and receiver.
- Learning about how to care for oneself and to recognize the significance of 'small things' that bring pleasure in the everyday.
- Responding to changes in the nature and balance of close relationships.
- Learning how to care for others so that this enhances the quality of their life and does not undermine your relationship with them.
- Deciding whether the investment required to build new relationships is possible and worthwhile in terms of their capacity to fill the 'gaps' left by the loss of people who have been close to you.
- Dealing with a sense of declining visibility, a lack of recognition of one's strengths and experience and, in some cases, identity.

People often feel alone in facing the emotional labour involved in making these responses. Their capacity to do so can be substantially enhanced by the support of others – including other older people. The observations of Age Concern staff about the importance of being with people and recognizing the situations they face, even if problems cannot immediately be solved, reflects an awareness of the importance of such attentiveness.

Associated with this type of labour is often a need for considerable planning and organisation. This can involve the everyday work of planning routes to the shops to avoid hills and ensure use of services close to bus stops; or reviewing the availability of public toilets, seating and other practical supports to make the experience of going out a source of well-being rather than something that reinforces a sense of loss. It can also involve 'bigger' planning, including difficult decisions about making changes in one's life – deciding how long it is feasible to remain living in a house that is not on a bus route; weighing up whether the view from an apartment that brings

pleasure compensates sufficiently for the struggle to get in and out because it is on the 10th floor; exploring whether it makes sense to invest time and energy in getting involved in new activities that may bring satisfactions, but also be demanding and the sources of further losses if they stop being possible. There is much emphasis on 'choice' in contemporary social policy. Older people have to make many difficult decisions that can be experienced as emotionally and organizationally draining rather than a source of empowerment. Once again, the way in which they are cared for and supported through these processes makes a huge difference to their well-being. We suggest that an emphasis on individual choice, rather than collective attentiveness to the impact of public policies on older people's lives, and on individual attentiveness to need, is insufficient to enabling well-being.

Learning to be well with older people.

To be well enough in old age requires a supportive culture in which to grow old. Thus the learning that is required to maximise well-being is learning that we all need to do: not only because most of us hope not to die young, but also because the capacity of older people to experience well-being depends in part on the actions, attitudes and behaviours of younger people. This reflects some of the points made above:

- We all need to learn how to give care that does not make the care receiver feel demeaned or a 'burden'.
- We need to learn how to respond to people who may have changed in important ways because of physical frailty, memory loss or because they are no longer able to do many of the things they used to do.
- We need to be sensitive to the tensions that exist between different values and to make good judgements about which should take priority in different circumstances. For example, when might an awareness of and concern for someone's safety override the need to respect privacy?

But this learning does not only involve those in close or intimate relationships with older people. It is not only family and friends, but service providers, policy makers, urban designers and strangers who encounter older people in their daily lives who need to recognize how their actions, behaviours and decisions can enhance or undermine well-being. The shape of urban spaces gives messages to older people about whether they are welcome there; how receptionists, shopkeepers, or bus conductors respond to and recognize older people can make a real difference to people for whom a weekly trip out is their only personal contact with the outside world. Importantly, the quality of health and social care services can impact on the well-being not only of those who are actively making use of such services, but on the confidence of those concerned that they may need to in future. Whether people are prepared to ask for help when they need it may depend on the response they think they will get if they do so. And underlying this is the way in which values shape policy. If 'care' is considered less important than choice, if the message is that 'independence' is the most important thing to aim for, then this can undermine efforts to promote the importance of caring relationships to well-being.

As we have developed this project we have drawn on thinking that has been discussed in terms of the importance of an 'ethic of care'. This is a perspective that recognises the importance of care as a value and practice both in personal relationships and in informing decision making about social policies. It is based in a belief that:

> …….people need each other in order to lead a good life and that they can only exist as individuals through and via caring relationships with others (Sevenhuijsen, 2003, p. 183).

One of our overall conclusions is that the promotion of ethical, relational practice based in an ethic

of care can be an important source of learning about how we can all contribute to well-being in old age. This learning can best come from maximising opportunities for people of different ages to interact personally, socially and politically, i.e. within the public spaces of everyday life, as well as the private spaces of family and friendship networks, in collaborations such as the one that generated this report, in the spaces of policy and political decision making.

Cultures, Structures and Resources

Whilst the findings of this study reinforce other work on well-being that indicates that this is not directly related to wealth or the material circumstances of people's lives, they do demonstrate that anxiety about having enough money can detract from well-being as well as reduce the options available to people. It is not helpful to suggest that 'happiness' does not have anything to do with money. In particular older people do worry about having enough money to pay for the care they need, now or in the future. In the current economic climate fears around future financial security and cuts in health and social care budgets may exacerbate older people's anxieties.

Our findings also demonstrate that it is important to understand how other differences that people have experienced at different stages, and sometimes throughout their lives, can affect well-being in old age. For example, the work that an older woman who has had learning disabilities, and who has lived in residential homes for most of her life, has to do to learn to be as well as possible when she moves in with a family is very different from the work required of a woman learning to adapt to be dependent on children she has supported for much of her adult life.

A general sense that old age can be a time of reduced control and decreased visibility suggests that it is wrong to understand well-being solely as a function of individual choices and capacities to adapt. Rather than thinking solely in terms of how individual older people can be 'helped' to be well, we need to think of how collective decisions about the way social life is organised, policies are made, particular characteristics are valued or de-valued and places are designed can all affect individual and collective well-being.

Our findings demonstrate that older people need to feel that both the physical places in which they live, and the social worlds they inhabit, are ones that recognise and include them. The World Health Organization (2002) has called this the need for 'age-friendly' communities and there are a number of practical resources that can help make such communities possible: good public transport, accessible public buildings, and good quality health and social care services; as well as a number of barriers, such as a lack of public seating, lack of public toilets, crowded streets, busy traffic, the decline of small shops / high streets, and the depersonalisation of services through increasing reliance on technology. The continuing recognition that is crucial to older people's well-being comes both from the attitudes and responses of those they interact with, and evidence that their needs are recognised in the way that physical environments are designed and services are delivered. Older people do not necessarily resist change, but may have to work harder than younger people to adapt to it. Thus, information and communication technologies can create opportunities for sustaining ways of being well, but not if they are not helped to use it or if they are simply seen as ways of reducing human contact.

Conclusion

The experience of working together on this project offers one example of the way in which, by involving older people in activities that cross age groups, it can be possible to learn about what is required to support well-being. We are not suggesting that we got everything right in the way we worked together, nor that the experience worked equally well for everyone, but we do think that the process of working together enabled both immediate experiences of the sort of relationships that can enhance well-being, and modelled the ethical, relational practices that our interviewees spoke about.

The initial view of the team that it was not adequate to research well-being amongst older people by measuring this using a structured questionnaire has thus been reinforced. To be well enough in old age is not only a process that has to be worked at, but also a function of both a lifetime of experience and the way in which older people individually and collectively are seen and treated by many different 'others'. Whilst the losses that often accompany old age can reduce resources to be well, survival and adaptation can also generate resources not available to younger people. Well-being is not something that can be achieved solely by being active in old age, but nor is it restricted to those who are able to maintain a high level of activity. It requires action by all of us, older people and those who hope to and will become old, to create the conditions in which our success in living longer is also a success in terms of ensuring old age is a time of well and not ill being.

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Appendix

Annonymised summary of biographic details of participants

(Ethnicity and disability as described by participants)

Phase 2

Name	Age	Gender	Status	Housing	Income	Work status	Ethnicity	Disability
Iris	88	F	Divorced	Own home on own	Comfortable	Retired	White English	Y (Osteoporosis)
Grace	97	F	Widowed	Own home on own	Getting by	Retired	White British	Y (difficulty in walking)
Margaret	83	F	Divorced	Sheltered housing on own	Comfortable	Retired	White British	Y (old age)
Susan	73	F	Divorced	Own home on own	Comfortable	Retired	White Scottish	Y (pacemaker)
Connie	87	F	Widowed	Own home on own	Getting by	Retired	White British	
Pam	79	F	Widowed	Sheltered housing on own	Getting by	Retired – voluntary work	White English	
Sally	67	F	Widowed	Own home on own	Getting by	Retired	White British	N
Elsie	81	F	Widowed	Own home on own	Getting by	Retired (cares for grandchildren)	White English	Y (eyes, legs – affected by stroke)
Richard	89	M	Married	Own home with wife	Comfortable	Retired	White British	N
Agnes	86	F	Married	Own home with husband	comfortable	Retired	White British	Y (Osteoporosis)
Eddie	85	M	Married	Council rented on own	Getting by	Retired (early to care for wife)	White British	Y (cancer, diabetes)
Samuel	88	M	Divorced	Private rented on own	Comfortable	Retired	White British	Y (back and walking problem)
Jacob	96	M	Married	Own home with wife	Comfortable	Retired (co-cares for wife)	White British	Y(COPD and mobility difficulty)
Rachel	74	F	Married	Own home with husband	Getting by	Working part time	White British	N
Ester	88	F	Widowed	Own home on own	Getting by	Retired	White British	Y (angina, arthritis)

Phase 3

Name	Age	Gender	Status	Housing	Income	Work status	Ethnicity	Disability
Joan	74	F	Widowed	Own home on own	Well off	Retired – voluntary work	White British	N
Kathleen	67	F	Single	Own home on own	Comfortable / getting by	Retired / long-term sick	White British	Y (back / spinal injury)
Charles	79	M	Widowed	Own home on own	Comfortable	Retired – voluntary work	White Welsh	N
Jennifer	76	F	Married	Own home with husband	Well off / comfortable	Retired – full time carer for husband	White British	N
Ethel	96	F	Widowed	Sheltered housing on own	Comfortable	Retired	White British	Y (back / limited mobility, hearing impairment)
Mary	75	F	Single	Lives with family / carers	Comfortable	Retired	White British	Y (loss of hearing and walking)
Ruby	84	F	Married	Own home with husband	Comfortable	Retired – voluntary work	White British	Y (deafness, arthritis)
George	86	M	Married	Own home with wife	Comfortable	Retired – voluntary work	White British	N
Rose	69	F	Married	Own home with husband	Getting by	Full time carer for husband	White British	N
Maude	85	F	Widowed	Sheltered housing on own	Getting by	Retired	White English	Y (mobility – knee and hip replacements)
Albert	89	M	Widowed	Sheltered housing on own	Comfortable	Retired	White British	Y (mobility- uses sticks or wheelchair, hearing aids)
Violet	90	F	Married	Own home with husband	Comfortable	Retired	White English	Y (loss of use of legs and arm following stroke, impaired speech)
Simon	73	M	Single	Sheltered housing on own	Comfortable	Retired	White British	N but diabetic
Reggie	90	M	Divorced	Sheltered housing on own	Struggling over basics	Retired	Black Caribbean/ British	Y (lack of energy, backache)
Peter	74	M	Single	Housing association on own	Comfortable	Retired	White English	Y HIV+

Focus groups

Phase 2	Women	Men	total
Focus Group 1 (Exercise)	4	-	4
Focus Group 2 (Activity)	8	-	8
Phase 3	Women	Men	Total
Focus Group 3 (BME women)	19		19
Focus Group 4 (Activity)	1	2	3
Focus Group 4 (Association)	13	-	13
Focus Group 5 (Association)	3	3	6
Focus Group 6 (Housing)	5	1	6
Total	53	6	59