Univ Brighton

E·S·R·C ECONOMIC & SOCIAL RESEARCH COUNCIL

Brighton & Hove age UK

Older people, well-being and participation

learning resources based on collaborative research

The handbook has been designed to be used with the lm Older People, Well-being and Participation. It was written by Marian Barnes, University of Brighton, Beatrice Gahagan, Age UK Brighton and Hove, and Lizzie Ward, University of Brighton.

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We want to thank them and the organisations for which they work, or in which they are involved, for their contributions to this project. These organisations are: Age UK Brighton and Hove; Age Concern West Sussex; Brighton and Hove City Council, Adult Social Care; East Sussex County Council, Adult Social Care; Brighton and Hove Older People's Council; Guild Care, West Sussex; Martlets Hospice, Brighton; Meridian Mature Citizens' Forum; East Sussex Seniors Association.

This work was funded by the Economic and Social Science Research Council, Follow on Fund. Award no. ES/J001058/1

The accompanying lm was produced by Loaded Productions. Still photographs come from that lm and were supplied by Angus Hubbard.

Contents

Learning Outcomes/Aims

The overall aims of these resources are to help those working with older people to develop ethical practice to enhance well-being. The lm and handbook will explain in more detail what we mean by ethical practice, but for now this really means good practice with a heightened awareness of all the things that might be important in enabling people to ‘be well’ as they grow older.

The research identi ed many different things that impacted older people’s well-being. But here we have focused on two main topics: supporting people in situations that involve them having to make dif cult decisions, and caring relationships in which older people are adjusting to changes in the way they can both give and receive care from others. We worked with a professional production company to create scripted scenarios based on interviews. In the lm these are acted to highlight key points identi ed by our interviewees, and to illustrate how social care workers might help people to think through some of the challenges they face as they grow older. The scenarios are intended to highlight issues to talk about, discuss and re ect on in the contexts in which you encounter older people. They are inevitably selective, and do not illustrate, her.9(,n whichT* y]TJ T* [ociaelh you encoun

When you have worked through this material you will:

1. Understand what contributes to well-being, in particular the importance of different types of relationships to older people's well-being.
2. Have explored how ethic of care principles can inform your practice and relationships with older people.
3. Understand ways in which older people can be supported to reach decisions that will contribute to well-being.
4. Been introduced to ways in which older people's collective involvement can enhance well-being, and enhance the scope for decision making.

groups who are campaigning for improved services. And they can also be used by other researchers wanting to research with older people in ways that can contribute to individual and collective well-being.

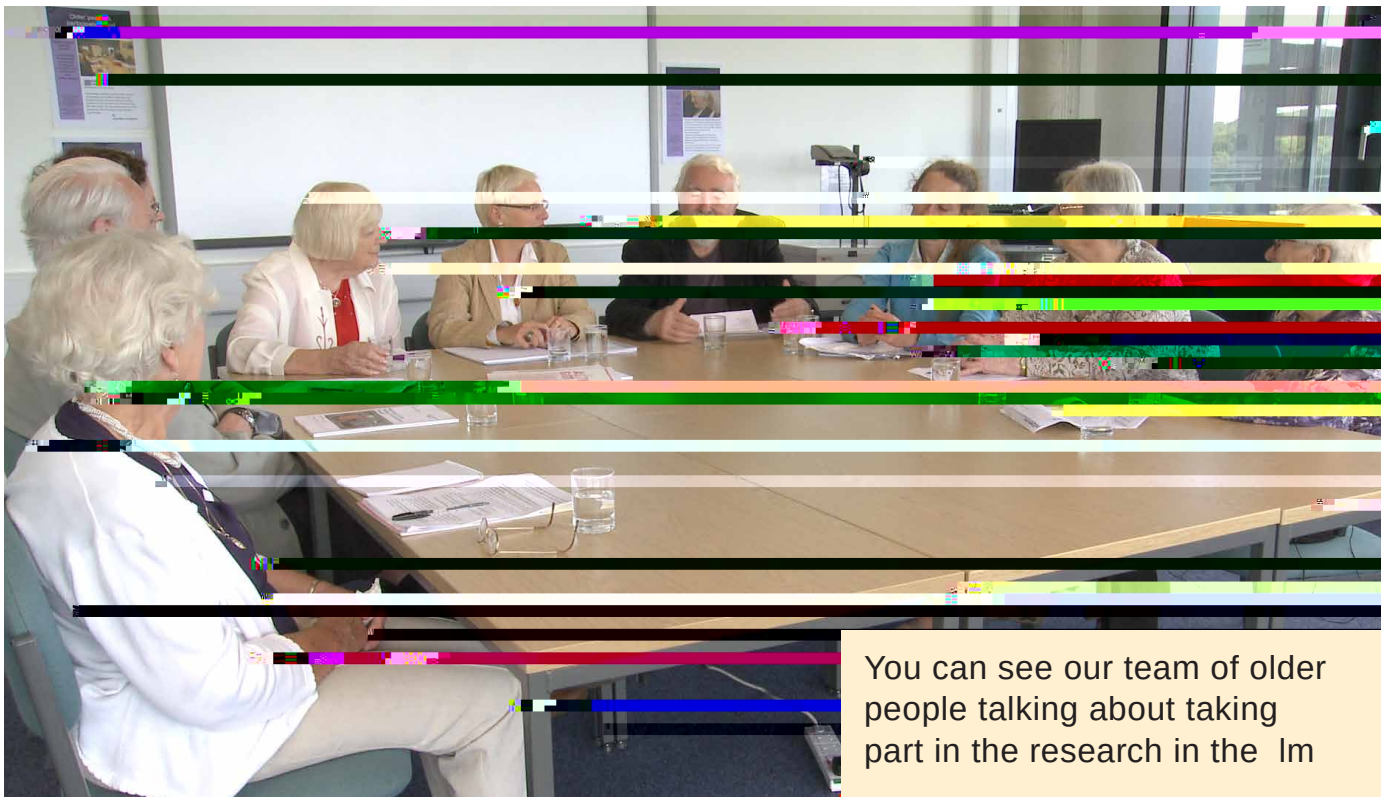
There are three sections in the handbook: well-being; developing good practice through an ethic of care; and participation. You can see all the themes and issues in the handbook captured in the lm which has the following sections: an introduction to well-being; adapting to change; supporting people in making decisions about where they live and the care they need; and working together with older people.

We hope that whether you are working in the statutory or voluntary sector, are a friend or family member, or are an older person supporting others close to you, you will nd this material helpful and interesting.

We hope you will take the time to use this handbook in conjunction with the lm. We have provided important background material which will greatly enhance what you learn from the lm and will help you to re ect on the questions and prompts that are provided. This is not a 'how to do it' guide, but a resource that will help you re ect on things that are important to all of us as we grow older.

What is Well-being?

Well-being has become a high pro le issue in contemporary policy and practice. Rather than talking just about ‘improving health’ we are more



You can see our team of older people talking about taking part in the research in the lm

younger. They talked in their own words and their own ways about what was important to them.

This has produced a rich insight into what is important to this group of older people and the ways in which different factors contribute to or detract from well-being. In this handbook we summarise the main points, but if you want to nd out more you could look at the full report on this project (http://www.brighton.ac.uk/sass/older-people-wellbeing-and-participation/) .

What do older people say about well-being?

We have summarised what we learnt under four headings:

1. People.
2. Health, Care and Support.
3. Resources.
4. Places and Environments.

The examples given here come from the interviews.

People

Not surprisingly, people talked about the signi cance of all kinds of relationships to their well-being. These included relationships with families, friends, neighbours, service providers, and also for some at least, the nature of casual encounters with strangers at bus stops, at the checkout counter of supermarkets and elsewhere.

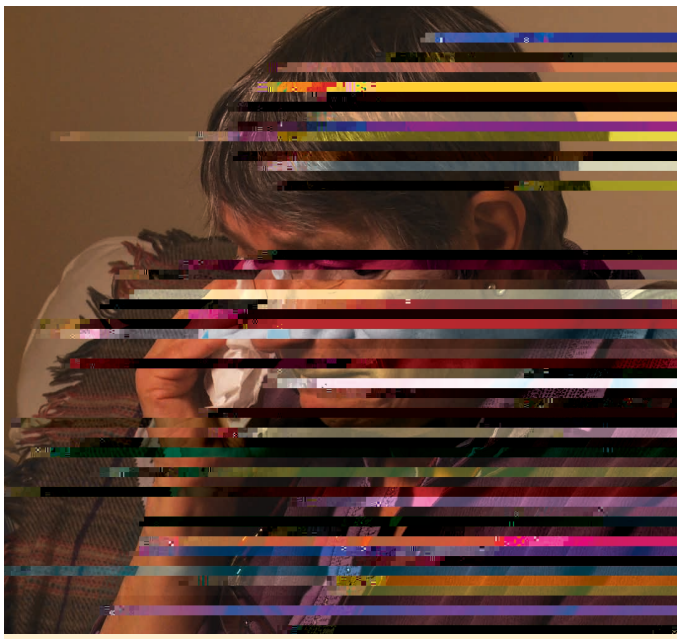
People feel a sense of security knowing a neighbour is looking out for them, and the opportunity to have a chat and cup of tea can help if someone feels isolated. The opportunity to strike up conversations in public spaces can also help people who have limited social contact to feel connected, particularly if family are rarely seen and friends have died. Losing friends can also mean losing the chance to share memories and some people suggested that, not only is it hard to make new friends in old age, ‘new friends’ do not carry the history that ‘old friends’ do. So that when people join in activities in the hope that they may develop new connections, this may not always positively contribute to a sense of well-being.

Automatic supermarket checkouts were avoided as they limit the opportunities for having a chat with other people or shop staff. The ways in which sheltered housing is designed, and the high turnover of residents in some blocks of ats, make it harder to get to know neighbours and do little to help with making connections to others - something that contributes signi cantly well-being.

Friendships are important at any age. The older people we interviewed talked about how friends contributed to well-being through offers of practical help, sustaining connections with their past, and also by enabling them to give back and contribute to the well-being of others.

Family relationships can be a source of support, security, joy and pleasure. They can also enable older people to contribute to others' well-being; not only caring for partners, grandchildren or other relatives, but offering their knowledge and experience (e.g. of places they have visited, journeys they have made) for the bene t of younger people starting out on exploring the world. Two way learning and support (e.g. grandchildren helping them use the internet) helps older people feel they are involved in reciprocal relationships, helps them feel valued, stay in touch with the world and maintain their sense of identity.

In contrast, being estranged from family with little communication with adult children can undermine older people's well-being. People may then feel they have outlived their usefulness and that the help they get from family is done only out of duty and is lacking in care (we look at caring relationships in more detail below). Older people can easily feel that they are getting in the way of others' lives and have become a burden.



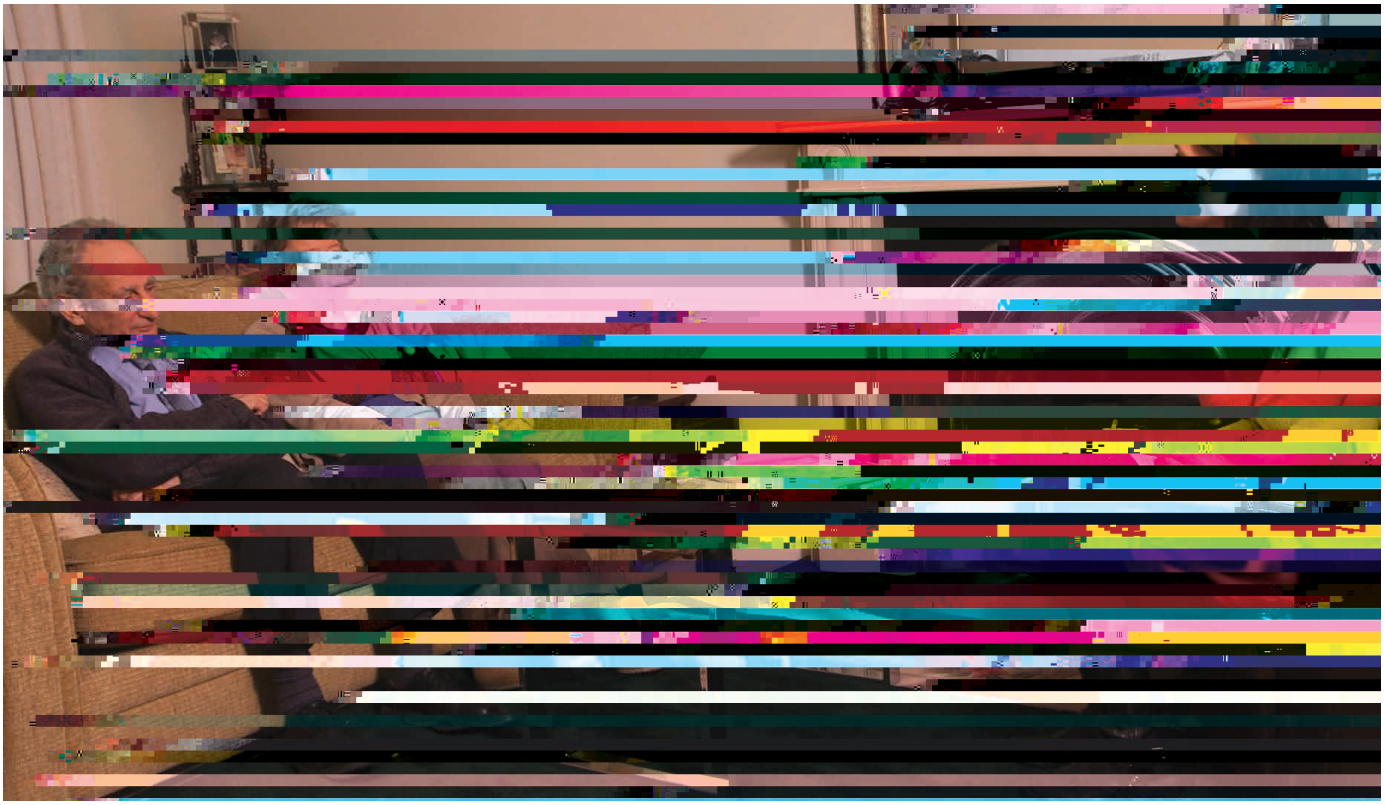
Health, Care and Support

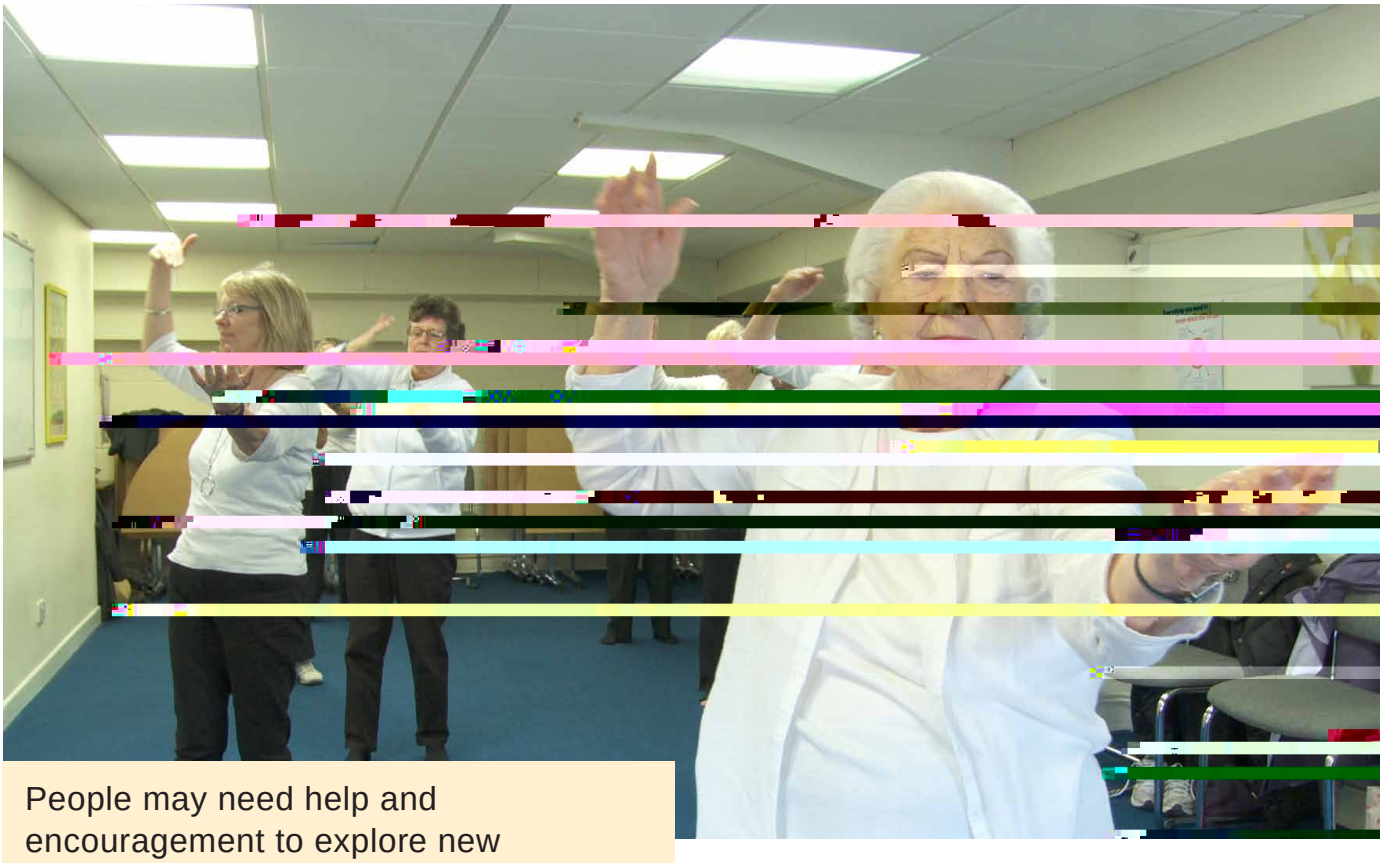
The linking of well-being with health: 'health and well-being', might make it seem that these two things inevitably go hand-in-hand. But is health necessary to well-being? Or alternatively, if people are unwell does this mean they can't feel a sense of well-being? Health was, unsurprisingly, a topic that came up frequently in the stories of the people interviewed for this study. For some people, being able to nd and get support from health services (for themselves or others), was a major aspect of their daily lives and the experience of this made a major impact on well-being. And for some, poor health was a signi cant barrier to well-being. Some people talked about the way their poor health got in the way of activities and social relationships that were important to them; whilst for others uctuations in their health caused uncertainties that meant constant anxiety and insecurity, as well as having to adjust their needs for help. Dealing with the emotional impact of poor physical health also caused anxiety, particularly when people felt alone in this, and in some cases fear of being ill in the future impacted on feelings of being well in the present.

But poor health and being unwell did not necessarily mean that older people felt they experienced poor well-being. Learning to adapt helped to reduce the negative impacts. One 84 year old woman reported that she could no longer swim in the sea after arthritis had led to hip and knee replacements. However, she still worked in the garden and meditated every day and got immense satisfaction from knowing the names of trees and owers. Having to cut back on physical activity and instead to focus externally and internally on noticing things in the present, meant she sustained a sense of being well.

And it wasn't just making these kinds of adaptations that in uenced whether poor health impacted negatively on well-being. People also spoke about how they were treated by health services. Being able to get the appropriate help, feeling listened to and cared for by health professionals affected the extent to which having poor health impacted negatively on well-being. Feeling that health workers were there for them, that appointments were easy to make and health services were easily located, meant older people didn't feel alone with their health problems and that someone was ready to work with them to address them. On the other hand, appointments which were made on the services' convenience rather than the older person's, doctors who appeared to show little real interest or engagement with the person, attention to computer systems rather than the person, and dif culty in getting to the service (because of transport or cost issues), meant being unwell was more likely to undermine well-being. Crucially it was the quality of the relationship with doctors, nurses and receptionists that made a difference.

It's not only computers and impersonal systems that can be a barrier to direct communication between workers and older people. Many social workers are tasked with completing lengthy assessment forms in a short space of time. In the nal scenario in the lm we illustrate how a social worker manages to establish a helpful relationship with her clients Patrick and Gillian without the very detailed assessment form getting in the way.





People may need help and encouragement to explore new activities that they may enjoy. But this can be hard if self-con dence has been lost and if the possibilities offered do not ‘ t’ the person. In the rst scenario Ellen shows the value of getting to know a person and what is important to them before exploring or suggesting possible options.

Financial resources are important and ‘having enough’ without having to worry about either the present or the future was a common theme. There were particular issues that caused anxiety and impacted on well-being, such as the costs of maintaining ats or houses and worries about the cost of residential care. It was clear that for many people careful management of income and expenditure was essential, but as Patrick and Gillian are experiencing (in the nal scenario), future uncertainty can make this hard – people simply do not know how long they are going to live.

New technologies can both contribute to and detract from older people’s well-being. Information and communication technologies (ICT) can be a means of keeping in touch when physical activity and travel become problematic. But it can also be a source of frustration if it is assumed that everyone has or wants access to computers and can create anxiety and contribute to people feeling out of touch with the contemporary world. Older people value ICT if it helps sustain and develop relationships, but not if it is seen to get in the way of interpersonal relationships.

Places and Environments

There are many ways in which both domestic and public spaces and places are important to well-being. Feeling secure in your own home is important and this is enhanced by knowing there are neighbours who can help in an emergency. Being able to look after your home is also important. If both of these aspects are lost it can lead to decisions to move to sheltered housing or residential care.

Being able to get about in the local area is important and this can vary greatly depending both on where people live and the availability of public transport. We have seen that accessing health services can be problematic, but more generally, enabling older people to feel connected to the locality in which they live and to enjoy what this has to offer is a signi cant factor for many in terms of their well-being.

Brighton and Hove (where this research was conducted) is a hilly city and, for some, this means that they are unable to get easily to the sea front - which is something that they would enjoy. On the other hand, the hills offer good views which some felt was important to them. It is also a lively city and many older people spoke of enjoying this – as long as public toilets and seats are available to give them con dence about being in public spaces. For others, this liveliness limited their con dence in being out and about and heightened their feelings of invisibility.

And it is not just access to physical space which is important. How older people experience places and spaces can depend on their interactions with other people within them and how ‘age-friendly’ the place feels. The way older people are treated in public spaces can impact on own their perceptions of themselves and whether they feel they have ‘a place in the world’ (or not).

As we have seen, ‘care’ plays an important part

Our research on older people's well-being revealed just how important care is in the lives of older people as well as just how complex and dif cult it can be to get it right. Below we offer some examples of the very different circumstances in which care giving and receiving was important to people.

Eddie had cared for his wife for most of their married life as she had developed post natal depression after the birth of their daughter, from which she has never completely recovered. She had lived in different homes and Eddie had battled to ensure she was well looked after. She now lives in a nursing home that treats her well and Eddie feels some satisfaction that he has been able to secure this for her. His sense of well-being is tied up with ensuring his wife is well cared for. He is now able to focus on himself – he has serious health problems of his own, and at last feels able to care for himself by giving himself a holiday. Whilst it has been important to his sense of himself that he has stuck with caring for his wife, this has come at

Sally cared for her husband who developed a neurological degenerative disease in his fties and was ill for almost 10 years before he died. Sally described

These examples illustrate not only the importance of care within close personal relationships, but the way in which this can be impacted by the presence or absence of care from others. People also receive care from friends, neighbours and volunteers, as well as from those employed to help them. This is one reason why these learning resources are not designed speci cally for social workers, occupational therapists or any other group of practitioners. We want to encourage all those who work with or support older people in different contexts to think about how they might help older people make some of the dif cult decisions they may face. We also want to encourage older people involved in groups or forums that aim to in uence policy and practice to think about how this way of thinking can help them.

Elsie is an 81 year old woman who is widowed and lives on her own in her own home. A year ago she had a stroke which was 'out of the blue' as she had been t and active until then. The stroke and her loss of mobility and sight have affected her con dence to go out and she is unable to do many things she previously enjoyed. Elsie has been getting reablement support to help her regain con dence to go out:

'I lost a lot of con dence so I was frightened to go like to restaurants or anything. I thought about it a lot and the anxiety always gets me in my chest you see, and my stomach, and I thought I can't do it, I can't do it, deep breath, I can't do it. The fear of crossing the road ....I just lost con dence... and I thought I can't go out ever again, For six weeks he walked with me, helped me cross over roads, fussing me, hold your arm because of my sight you see, with going into the road, I then just did, then gradually after a time I let his arm go'.

Ethic of Care principles

Whilst most people want to be 'independent' and much social care practice is designed to enable people to be as independent as possible, this usually involves ensuring different kinds of help is available, and much of this help is provided through relationships with older people. This could be personal care such as bathing or nail-cutting during which the care worker not only carries out the speci c task involved, but also chats and demonstrates an interest in the older person, or it could be the help provided by an occupational therapist to develop new activities when isolation or poor health has meant that an older person has stopped doing things that used to give them pleasure. It could also be the support offered by a volunteer to help build con dence after an operation – as in the case of Elsie:

Care ethics prompts us to think about how connections with others can be practiced in ways that contribute to well-being. Rather than focusing on 'independence' per se, it focuses on the type of relationships necessary to ensure people can do what they want to do. And because our relationships with others are not only a matter of personality and personal history, but are affected by our gender, class, ethnicity and sexuality, an ethic of care calls attention to the importance of understanding the speci c contexts in which relationships take place. It reminds us that to be 'person-centred' we need to understand people's backgrounds as well as their current circumstances and relate to them as unique individuals.

The examples we have given of people negotiating care for others and for themselves in different and changing contexts, demonstrate that care can be complex and hard to get right. It is far more than just being concerned about another person. So it is useful to have a framework within which we can think about what is involved and how we might ‘do care’ in practice.

One of our interviews was with Mary, a woman with learning disabilities, who was learning about family life:

Mary is 75 and lives with a family in their home under a scheme that matches people with learning disabilities to family carers. At the time of the interview she had lived with the family for almost two years, but previously she had lived in residential care since childhood. For Mary, ‘ nding’ a family in older age has been the source of well-being. She spoke about going on outings and celebrating birthdays with her foster family 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:

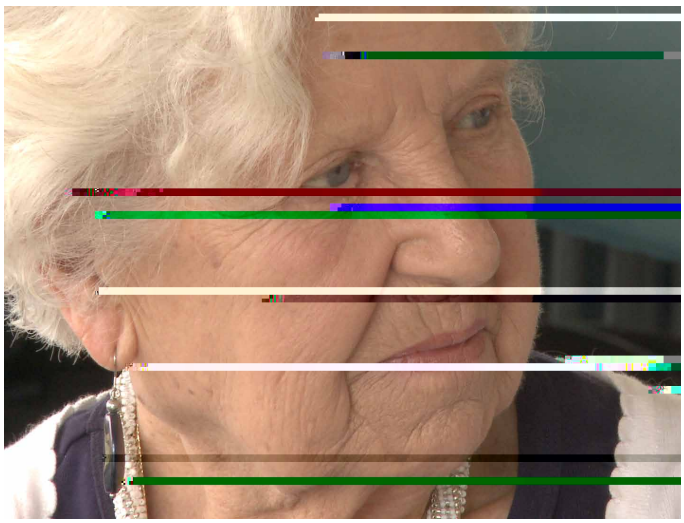
‘I mean if we upset each… if I think I’ve upset her then I go away and I come back and I say to her, “Did I upset you, are you all right now, I upset…”, and I sit here, I sit in wherever I’m down, and I phone her up and say to her, “You all right ?”, “Yeah, I’m all right, are you?” you know, and this is how we get round it’.

These four phases of care are associated with four principles that we can apply to the way in which relationships can be established with older people. In the four scenarios that are acted in the accompanying lm, we can see the different workers demonstrating what this looks like in practice. The commentary on those scenarios highlights this.

1. First of all, Attentiveness refers to the need to be aware of and understand the needs of others. This requires an other-directed active listening, and a focus on the individual, their relationships with others and the social, cultural and economic factors that affect their situation. 'Carrying out procedures', such as working through an assessment schedule, without actively listening to what the person is saying, how they are saying it, and, equally importantly, what they are not saying, can amount to inattentiveness.

   But talk can be just as important to attentiveness. If you respond appropriately to what the other person is saying, this demonstrates that you are listening and understand. And this, in turn, can help the other person talk more about themselves and to re ect on what is important to them. This can be particularly important when they are facing issues they have not had to face before and that they may not want to think about, such as the possibility of a move into residential accommodation.

   We need to be attentive to our own needs for care in order to be aware of the needs of others. But that does not mean we should assume that how we would feel in this situation is how the other person is feeling – it is not about putting ourselves in the other's shoes but being attentive to their circumstances, the way they are feeling and what is important to them.



2. Responsibility . Attentiveness to need is necessary before care can be given, but attentiveness without action to follow does not deliver care. Care is not simply an emotional disposition towards another, but involves accepting responsibility to act on the basis of the need that has been understood. What exactly we should do in a particular situation depends on the understanding generated by attentiveness. Assuming responsibility to act on the basis of attentiveness to the needs of older people and those who are important to them requires the capacity to 'judge with care', in relation to the particular circumstances of the person or people concerned. Whilst workers may have speci c procedures that they have to work through, this is not an unthinking process – you need to consider how these relate to and affect the particular person you are working with.
3. Competence . This means that the work of care has to be performed competently for care to have been given. This re ects the failures of work that is called care, but in fact does not deliver care and may, in some cases, be abusive. For example, a nursing assistant who leaves food or drink out of reach of an old woman in hospital who thus becomes dehydrated is not giving care. It does not produce the outcome that the work of care should achieve. So this principle asks us to be aware of the results of what we do.

4. The fourth principle is that of Responsiveness . We are often encouraged to be ‘responsive to’ the other person, but in an ethic of care framework responsiveness means something rather different. Here it refers to the response of the person receiving care – how are they experiencing the care that is being given, and what does it mean to them? So it emphasises the importance not only of being attentive to the needs that people have, but what they can contribute to the process of care. What knowledge do they bring that will be useful to meeting their needs? Is the help that is being given something they feel comfortable with? What effect is it having on them? This principle recognises that those receiving care are active contributors to the relational process of care. They have knowledge /feelings and understanding to contribute to this and thus giving and receiving care should involve a dialogue between those involved in which both can learn from the other. Care often takes place in situations in which one person is more powerful than the other. And, as we have seen, it can be hard for people to receive care and this can sometimes mean they are hard to care for. The challenge is to be aware of how people respond to care and what this means for the way help can be provided.

All these principles need to be evident in practice for the relationship involved to constitute a caring relationship. This has been called the ‘integrity of care’. Other p in is mied to be evidenmtr p t me>f care. What knty of contribute to th soostv(ovidedcon7.8(ecef car)17ntributors tve,hey brs it7.9(e toas7.9(ocess)20(e thus)20( )]TJ d foay)19 syou

3 Participation

The third element of these learning resources concerns ways in which people can take part in shaping decisions that affect their lives. This includes both situations in which older people need to reach decisions about 'what to do' in response to changes in their own lives (such as illness, disability, loss of family or friends), and situations in which older people collectively can take part in shaping knowledge, policy and practice that affect older people generally. We start with older people's involvement in decisions about their own lives – these are the type of decisions that the people in the four scenarios are facing up to.

Partnership, shared decision making and choice

The need to develop ways of enabling older people to play an active part in decision making, rather than simply 'take what they are given' by service providers who claim to 'know best' what they need, has a long history. For example, in the late 1980s/early 1990s work on 'partnership practice' in social work was designed to develop ways in which social workers would work with their 'clients' to determine their needs. At the same time, in the context of clinical practice, a similar idea of 'shared decision making' was intended to encourage doctors to recognise the importance of making decisions about medical treatment with rather than for their patients.

These initiatives, and the broader development of consumerism within social care services, were responses to the lack of power felt by service users to determine what help they received, how, when and who provided it. They also re ected a genuine commitment on the part of some workers to enable service users to be part of the process of nding solutions to their problems. Although work on 'partnership practice' also highlighted the way some social workers thought they were working in partnership when this was not the way their clients experienced it.

The transformation of 'clients' into 'consumers' of services heralded the emergence of 'choice' as the means by which power could be shifted from those providing services to those using them. But during the 1990s there were many critics of this strategy. Reasons for criticizing choice and other consumerist mechanisms as the way of 'empowering' service users included:

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  which people could choose.
- s 4HE LEVEL OF INFORMATION AV
  options, and the extent to which experience of what using the service would be like could be predicted from available information.
- s 4HE IMPLICATIONS OF @EXITIN
  found to be unacceptable.
- s 4HE UNEQUAL CAPACITY AND R
  to people to choose and the likelihood that this approach would bene t the strongest.
- s 4HE FACT THAT MOST SOCIAL C
  based in interactions between provider and recipient – they are not 'products' that can be bought 'off the shelf'.

Nevertheless, the promise of choice has endured. It has been promoted by some disabled people who want to control the support they receive as a means of controlling how they live their lives. Some have argued that self-select, self-manage schemes such as those where people choose and employ their own personal assistants is the way in which they will be able to live their lives as they wish. This has driven the move to transform social care services via self-directed support, personal

budgets and direct payments. What is much less clear is that such mechanisms work well for older people, particularly those who are very frail and isolated. Early research on the implementation of personalisation indicated that older people were the group least likely to be positive about this way of enabling them to access services.

We can draw from our well-being research to suggest why this might be. Firstly, many of the decisions that older people may have to make are not ones they really want to have to make. Often this relates to situations of loss where they feel they have to give up things they would really rather not – in particular giving up a home they love because they can no longer manage this. In this situation they may nd it hard to choose, or select, from a series

their lives and the lives of other residents. What was important in this context was the trust and collective empowerment that was generated by the women working together, and this came about through time and space being given for exchanging experiences. And once again, the role of an attentive facilitator was fundament to this process.

Two members of the team that worked on developing these learning resources were involved in the Meridian Mature Citizens