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Older people, well-being and participation

learning resources based on
collaborative research



The handbook has been designed to be used with the film 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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University of Brighton



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Introduction

These learning resources are designed to help anyone who works with older people to maximize well-being in older age. They are based on participatory research carried out by a team of older people, university researchers and a voluntary sector manager. This explored what well-being means to older people and how it is generated. We then worked with some members of the research team and statutory and voluntary sector practitioners and trainers to produce a film and this handbook. So this material is based not only on what we found out about older people and well-being, but what we learnt from working with older people and with practitioners. It draws from different types of knowledge and expertise, but the starting point is what is important to older people.

This handbook accompanies the film and provides more detailed explanations of the issues we explore through the acted scenarios. It also lists questions that you can use to reflect more on these issues, and suggests where you can go for more information.

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 film 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 identified 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 difficult 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 film these are acted to highlight key points identified 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 reflect on in the contexts in which you encounter older people. They are inevitably selective, and do not illustrate, for example, the complete process of carrying out a social care assessment. Our focus is on the way workers can practice in a person-centred way, rather than more technical issues of assessing needs.

The film starts by describing the way in which we went about this project and we also reflect on what we have learnt about ethical practice in working with older people collectively in carrying out the research. You will see members of our research team talking about what they learnt about well-being and about their experiences of taking part.

These learning resources can be used by those providing training for social care and social work practitioners in both statutory and voluntary sectors, and by those providing education in social care in colleges and universities. They can also be used by groups of staff wanting to reflect on their own practice and by older people's



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 film 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 find this material helpful and interesting.

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.**

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

1 Background – Well-being

To give you some background information to these resources we start with the idea of ‘well-being’.

What is Well-being?

Well-being has become a high profile issue in contemporary policy and practice. Rather than talking just about ‘improving health’ we are more likely to read about ‘improving health and well-being’, and similarly, the notion of ‘welfare’ is now accompanied by ‘well-being’: as well as ‘doing well’, the aim should be to ‘be well.’ Well-being has been associated with ‘happiness’, with ‘quality of life’ or ‘life satisfaction’. And sometimes it is talked about as ‘subjective well-being’ or ‘mental well-being.’ So the idea of well-being involves how we feel about ourselves and our lives, rather than how our lives might be assessed by others.

A large industry has grown up amongst researchers and policy-makers intent on finding ways in which we might measure well-being alongside more objective measures of things like health and economic status. And much current social policy is based on ideas about what contributes to well-being. In relation to older people and others who use social care services, the importance of ‘activity’ or ‘healthy lifestyles’ are highlighted as factors that contribute



to quality of life, well-being and remaining independent. This is also based on the idea of ‘choice’- that we can benefit from choosing how we live our life and what services or supports will help us do so.

Our research

Our research was designed so that older people could talk about what well-being means to them, and what helps them experience a sense of well-being. When we started out on the project, we invited the team of older people working with us to try out one of the commonly used questionnaires designed to measure how much well-being older people experience. This is based on four concepts: control, autonomy, self-realisation and pleasure. The questionnaire is a series of statements, such as: ‘I feel satisfied with the way my life has turned out’, with four possible responses to select from: ‘often’, ‘sometimes’, ‘not often’ or ‘never’. Team members responded to this in a number of ways. Some suggested that how they filled it in would vary from day to day (and possibly from hour to hour) depending on how they felt and what was happening at the time. Some suggested that filling it in could make you depressed. A number of people commented that it didn’t take account of older people’s relationships with others, and from their point of view such relationships were crucial to understanding well-being.

So we adopted a very different approach in our research. Our older team members interviewed other older people and asked them to talk about circumstances in which they experienced well-being, what this meant to them, what produced feelings of well-being, and how this might have changed over the years. Those interviewed told stories about their lives now and when they were



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

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 find 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 significance 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 flats, make it harder to get to know neighbours and do little to help with making connections to others - something that contributes significantly 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 benefit 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.



May's experience in the two film scenarios illustrates one way in which relationships with family and friends can impact well-being.

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 find 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 significant 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 fluctuations 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 flowers. 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 influenced 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 difficulty 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 final scenario in the film 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.



Giving and Receiving Care

Older people not only receive care from family and friends, but also often give care to others. The way both types of relationship are experienced is an important factor affecting their well-being. As we already mentioned, older people may find it hard to receive care, but if they feel they can also give care to others it may be possible for them to retain a sense of their own self-worth and identity and make it easier to come to terms with their own need for help.

But other things also make a difference. If people get a positive response to their requests for help, they feel less of a 'burden' and they can experience well-being from being well cared for. One 97 year old woman who could not get out of the house without assistance described the difference in the way a young friend treated her when he took her shopping in comparison with her son's response. The friend made the whole experience a special treat that he enjoyed, while her son treated this as a task to be dealt with as quickly as possible. Her response to this was to say she would never ask her son for help: 'I'd rather crawl on my hands and knees'. Wanting to remain 'independent' here may be a response to an absence of caring support rather than what older people actually wish for.

May's scenarios are based in part on what this woman told us.

It can be very satisfying for older people to be able to care well for others and this can contribute to their own well-being. But both care giving and care receiving can be associated with a change in a person's role and identity that often requires some adjustment and negotiation. Women caring for their husbands can find themselves in a position where they have to take on tasks they would prefer not to have to

do, such as car maintenance. But both women and men may also value their roles as carers, including situations where they take on more public roles, such as advocates for other carers. Carers also need help and support to ensure that their own needs are met.

Resources

The stories older people told in the interviews demonstrated that it can be hard work to sustain and improve well-being and that learning how to be well in old age requires a number of different types of resources.

Age itself can be a resource. Lifetime experiences help inform attitudes in the present and enabled some people to reflect on what they had learnt about themselves and others. Memories can generate pride in past achievements and sustain a sense of continuity and self that is important to well-being.

For some, faith and spirituality were a resource to be drawn on and provide a bigger perspective and sense of meaning. For others, focusing on the 'here and now', recognizing the need to adapt and making the most of their personal and interpersonal resources, were identified as important to well-being. This not only affected the present, but also helped in thinking ahead and planning for possible future needs without anxiety or fear.

People also talked about more practical resources that were important. These included taking part in activities that offered a sense of purpose and connection. But for those who were older and more physically frail, many activities were no longer possible and the loss of activity (such as the woman who had been told in her early 90s that she was too old to continue to work in a charity shop) could detract from well-being.



People may need help and encouragement to explore new activities that they may enjoy. But this can be hard if self-confidence has been lost and if the possibilities offered do not ‘fit’ the person. In the first 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 flats 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 final 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.



In the film it is not only Gillian's increasing frailty that has led her and Patrick to consider different living options. He also talks about neighbours having moved away as making them think about a possible move.

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 significant 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 confidence about being in public spaces. For others, this liveliness limited their confidence 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 in what older people have to say about well-being. In the next section we consider a way of thinking about care that we think is useful in developing practice for supporting older people.

Questions and reflections:

- **How is well-being thought about where you work or volunteer? Is this very similar to or different from the way in which we have described older people's responses to well-being here?**
- **In what ways might the way in which you relate to older people affect their well-being?**

You can think about this in several different ways: in terms of the work you do; how you feel about ageing yourself; the way you interact with friends or family members; the way in which you respond to older people you know and work with, and the way you interact with older people you do not know.

2 Developing good practice – Introducing an ‘ethic of care’

The word ‘care’ has often had a bad press. It has been linked with poor and sometimes abusive practice, and has been seen to be in conflict with people’s wishes to be in control of their own lives. If you work in social care services you may be discouraged from thinking that care is a ‘good thing’ and instead be encouraged to think about ‘support.’

But should we abandon care as a value on which to build supportive and helpful services for older people? If we think about the frequency with which we use the word ‘care’ in all its guises: caring, careful, careless, it is hard to imagine that care doesn’t matter to people. And whilst other words such as help or support have been adopted as alternatives to care, can we understand what ‘good support’ might look like without drawing on the values we associate with care?

We want to introduce you to a positive way of thinking about care that doesn’t see people who receive care as passive. As we have seen, our research highlighted how important good care is for older people. In this section we introduce you to ideas about ‘care ethics’ that emphasise care as a relationship that involves both giving and receiving and which is necessary to enable well-being. We link these ideas to ways of helping people make decisions through conversations that enable people to think about what is important to them.



Care as practice and values

Work on an ‘ethic of care’ has been developed by psychologists and sociologists wanting to understand how care takes place in intimate relationships, by political philosophers considering what values shape public decision making, as well as by social work, nursing, educational and other practitioners reflecting on relationships with service users. This suggests we can think of care in at least three ways:

- as a quality in relationships (friendships, kin relationships as well as service provider/ service user relationships);
- as a set of values or principles that can guide the way we make decisions,
- and as a form of practice.

An Ethic of Care is important for us all

Care is important for all of us. All of us need care as babies and children and few of us would be happy with a life in which we felt uncared for or unable to care for others. Even as workers if we don’t feel our employers care about us we might find it hard to do our job well and we need to recognize our own needs for care as well as the needs of others.

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 difficult 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 a price. His daughter will have nothing to do with him as she thinks he should have left his wife and this is a source of sadness for him.

Elements of Grace's story are echoed in the scenarios involving May in the film. Here we provide some more details from the interview with Grace.

Grace does not experience her relationship with her son as supportive of her well-being. She describes the way in which he provides a very functional response to her need for help with shopping. When her daughter-in-law comes there is no conversation in the car. Grace says she doesn't understand the distance in their relationship, or why her son and his family make little effort to be with her as they have never had an argument. She describes this as *'it's just as though I don't exist'* and says she feels that she is living too long for them. She has no sense of being cared for by them.

Because of this she is reluctant to ask for their help: *'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'*.

In contrast, a friend's son makes her feel *'just like the queen'* by making a shopping trip into a special outing, looking after her in the car, giving her time to look around, talking to her about prices and bargains. As well as providing practical help he shows he cares for her and enjoys providing her with these special outings.

So although Grace seeks to be independent, this is not because she values independence in its own right. Rather she has learnt not to expect help from her family. In answer to a suggestion from the interviewer that she liked to make her own decisions she said: *"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?"*

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.

Sally's story highlights both the changes that can take place between husbands and wives when one becomes ill, and the importance of developing positive relationships with paid care workers. It is important to Sally to receive recognition for the care she provides, as well as practical help from workers.

Sally cared for her husband who developed a neurological degenerative disease in his fifties and was ill for almost 10 years before he died. Sally described how life changed from them being busy, active and social people as her husband's condition deteriorated and he could not communicate or walk. She talked about the emotional demands of caring for her husband who deteriorated from being 'a brainy, clever, brilliant man who was so active' to someone who 'couldn't speak, couldn't swallow, couldn't move, but his brain was still completely active'.

She talked about having to fight for a lot of things for him – machines, special beds and equipment- so that she could care

for him properly. She had paid carers to help shower him every day because he couldn't stand and she talked about the relationships they developed with these helpers:

'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 and some of the others as well, ...the district nurse, was very good and she used to come and she used to say, anything you want, because you're doing a wonderful job, you wouldn't think there was a sick person in this house...'

In both Eddie and Sally's case it is clear that one partner needs more help than the other. But people both give and receive care at different times in their lives and, particularly in the case of older people, it may not always be helpful to label one partner as the carer and the other as the care receiver. The scenarios involving Patrick and Gillian in the film echo some themes from an interview with Jacob and his wife Esther which we look at next. One of the challenges we have highlighted in the acted scenarios is the wish of couples to stay together as they grow older and both are becoming more frail.

Jacob is 96 and lives with his wife Esther, who is 90, in their own home. They described themselves as 'comfortable' in terms of their income and Jacob had previously worked in a professional occupation linked to the health service. Both of them have deteriorating health (he has COPD and his wife has mobility difficulties and is partially sighted). Their needs for support in daily living - running the household, shopping, using transport and getting to frequent hospital appointments – have increased and they have been trying to find appropriate support to help them manage.

They do not want to depend on their family and they think that it is their responsibility to find solutions for their needs themselves. They thought they should explore options for residential care and had done so by booking respite stays in two different homes. One was good, but they were very unhappy in the second, in part because the staff seemed uncaring, and this has left them quite fearful about where they might end up.

So in the meantime they get by helping each other with the tasks that each can manage, although Esther, in particular, is clearly exhausted by the responsibility of looking after the home.



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 specifically 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 difficult decisions they may face. We also want to encourage older people involved in groups or forums that aim to influence policy and practice to think about how this way of thinking can help them.

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 specific 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 confidence after an operation – as in the case of Elsie:

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 fit and active until then. The stroke and her loss of mobility and sight have affected her confidence to go out and she is unable to do many things she previously enjoyed. Elsie has been getting reablement support to help her regain confidence to go out:

'I lost a lot of confidence 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 roadI just lost confidence... 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'.

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 specific 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.



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, ‘finding’ 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’.

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.

Caring has been identified as comprising four phases which we illustrate here with the example of personal care services.

- 1. Caring about** – recognising that there is a need to be met. This involves, for example, policy decisions that the state should take responsibility for ensuring older people who are unable to wash and dress themselves should receive help to do so.
- 2. Taking care of** – assuming some responsibility for ensuring that the need that is identified can be met. This relates to the establishment of a service that can provide bathing and personal care, and that service providers have the necessary skills and resources to do the work of care.
- 3. Care-giving** – this is the ‘hands on’ work of providing care. So, in this case, this is the work undertaken by bathing assistants and care workers who visit older people to provide personal care to enable them to carry on living at home.
- 4. Care receiving**- the response of the person receiving care. This includes both the way in which the person contributes to the process by indicating how they prefer to be bathed, and the degree to which they feel their needs have been met by the way in which the service has been provided. The way they experience and respond to their care can also have a big impact on the care givers. Because people may not want to receive care they can sometimes resist help and this can make it hard for those offering to help.

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 film, 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 reflect 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 specific 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 reflects 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 principles have also been suggested as important. One is trust, recognising that in many caring relationships one person is likely to be more vulnerable than the other and thus they need to be confident that they can trust the more powerful person. Another is reciprocity, reflecting the importance to most people of feeling that they can give as well as receive care. This may be one aspect of the way in which the principle of responsiveness can be demonstrated. We know that if older people feel they can care for someone else it may be easier for them to receive the care they need.

Questions and reflections

1. In what circumstances do you need and or receive care? Think about this in its broadest sense, not just physical help, but how you feel about how others respond and relate to you in a range of different relationships.
2. How do you respond to this?
3. What does 'good care' mean to you?
4. What do you like about being cared for?
5. What do you find difficult about care?
6. How is care different from support?
7. How can you apply the ethic of care principles to yourself and to your interactions with older people?

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 reflected a genuine commitment on the part of some workers to enable service users to be part of the process of finding 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:

- The extent to which alternatives existed from which people could choose.
- The level of information available about options, and the extent to which experience of what using the service would be like could be predicted from available information.
- The implications of ‘exiting’ a service if it was found to be unacceptable.
- The unequal capacity and resources available to people to choose and the likelihood that this approach would benefit the strongest.
- The fact that most social care services are 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 find it hard to choose, or select, from a series of alternatives, none of which they really like. Nor can they anticipate what it will be like to live in sheltered accommodation, for example, when they have always been used to having a house of their own. Making decisions like this requires exploring feelings that might be very difficult to confront. Choices are unlikely to be solely 'rational', but also have a significant emotional content. Good information alone may not be enough, and 'choosing' may not feel 'empowering'.



Secondly, to understand the decisions that older people have to make as 'individual' decisions does not reflect the significance of close and more distant relationships and the interdependencies that are so important to older people's well-being. Older people may feel that their decisions are constrained by their relationships with others, and that they should or want to make decisions with others because others are involved in and will be

affected by these decisions. So the process of decision making may be better understood as one in which two or more people are involved in discussing, exploring and negotiating, rather than in which one is making an individual choice.

Thirdly, and again reflecting the importance of relationships to well-being, older people's accounts emphasise that the help they receive, both from family members and from service providers, depends on the quality of the interaction. As we noted, some talked about the barriers erected in interactions with their GPs by constant reference to computers. What they are looking for from those who are helping them is someone who is focussed on them and the situation they are in, and who they can trust to be with them through a process that may need some time to resolve. If they feel the emphasis is on systems or procedures that are predetermined, they are unlikely to feel empowered in the process of decision making.

And finally, for those whose frailty and extreme old age has created a weariness with the need to make frequent changes in their lives as the world feels like it is closing down, there can be a genuine desire for others to suggest solutions, rather than them having to choose. Being able to trust that the solutions offered will be attentive to what is important to them, and will respect their self and their needs may be more important than being in control of the process.

So rather than thinking in terms of simply offering choices, a process of helping older people reach decisions can be guided by the ethic of care principles outlined in the previous section.

Older people shaping knowledge, policy and practice together.

As an emphasis on 'choice' was emerging in policy and practice, an alternative perspective was offered by those promoting the 'voice' of older people and other service users in shaping policy and practice. Often voice was understood as collective voice: opportunities for service users to get together to develop their own ideas about what their priorities are, how services should be designed, and what policies best reflect their preferences. Similarly, in the area of research practice, there have been increasing opportunities for older people to take part in research that can generate new knowledge and understanding of older people's lives and what is important to them. Again, this usually involves groups of older people working together with younger researchers, to carry out projects. Through these more collective mechanisms older people can be involved in shaping the policies, practices and services that might contribute to their well-being. And involvement itself can directly contribute to that well-being through offering recognition of what older people can contribute, as well as providing experiences of caring relationships in the context of working together.

In our work with older co-researchers we sought to apply ethic of care principles to our practice. This involved being attentive to the different needs of a diverse group of older people, taking responsibility for ensuring that they could make the input that worked for them and that they received the support necessary for them to do so. It involved ensuring that we enabled everyone to contribute to the competent completion of the research. And it required us to be aware of how participants were responding to taking part and that any upset or difficulty that they experienced in relation to this was addressed.



In the film you will see members of our team talking with us about their experiences of working in this way and what was important to them about this. Although this way of working involved researching together, the principles underpinning it are equally relevant to cases where older people take part in processes of service provision.

Another, rather different, example comes from work developed by Age Concern Scotland in Fife in the early 1990s. This involved working with 7 groups of older people who were all intensive users of community based health and social care services. Again, attentiveness to the different needs of members of these groups in relation to their participation underpinned the success of this project. The competent leadership provided by the facilitator meant that people felt enabled to participate effectively – one participant referred to the way in which the facilitator 'knitted' contributions in a way that suggested she enabled the whole to become more than the sum of the parts. The way discussions were conducted can be understood as 'care full deliberation' – discussions that recognise the emotional and well as rational dimensions of older people's lives and experiences, take these into account and respect these.

Another context in which it is important to think about how older people collectively can be involved in ways that can enhance well-being is residential care. An interesting example of this comes from work in the Netherlands. 'The Taste Buddies' are a group of older women living in a residential home who came together to improve the quality of food within the home, and through so doing also improved the quality of



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 fundamental to this process.

Two members of the team that worked on developing these learning resources were involved in the Meridian Mature Citizens Forum – a group in East Sussex that gives older people a voice in shaping policy, and another was a member of the Brighton and Hove Older People’s Council. This is an elected body representing older people’s views and perspectives to the city council. There are now many different examples of spaces in which older people are getting together to try to shape policies, services and the way they are provided. There are different contexts and models for older people’s collective involvement. But regardless of whether this is focused on doing research, speaking directly to policy makers, or engaging residents in the day to day lives of residential homes, care full deliberation will involve:

- Enabling people to talk about the personal and interpersonal experiences associated with ageing, being attentive to such experiences and demonstrating that they are recognised and respected.
- Being attentive to the different practical and emotional supports that are necessary to enable different older people to contribute. This includes being aware of the way in which people are responding to taking part and checking out why some might find it difficult.

- Recognising the importance of the knowledge that comes from the experience of growing older that is not directly accessible to those who have not yet experienced this.
- Being prepared to attend to what people are saying even if this is being said in ways that are unfamiliar to you, or if it is not what you want or expect to hear. This includes being open to emotional responses and voices and recognising what these might be telling you.
- Recognising when what older people say indicates that there is a failure in services, when you might need to re-think, or when there is evidence of lack of understanding and preparedness to listen.
- Being prepared to act in response to what has been said and to let people know what has happened as a result.

Questions and reflections

1. When you have difficult decisions to make, what kinds of factors affect your ability to do this: emotional factors, the impact of your decision on relationships with others, anxieties or uncertainties about future consequences of your decision?
2. How do you go about making decisions? Do you talk to others? If so, what sort of help are you looking for from them?
3. Thinking of older people you know, what would help them get together to share their ideas about, for example, what is important in where they live as they get older?
4. How does your service enable older people to share their experiences and ideas with each other and with those who provide the service?
5. How does your service ensure the individual as well as collective voices of older people are respected and heard?

In conclusion.....

In many ways what we have been exploring with you in this handbook and the film that accompanies it might seem very obvious. Of course we know that how others treat us is important to our well-being, and that we need to feel that we can reach our own decisions (with help as necessary) about how we live our lives as we grow older. But we hope that we have helped you become more aware of what this means in terms of the different type of relationships we need to develop in our personal and professional lives, and that we have offered a framework that can help structure how we go about establishing such relationships. Our aim has been to encourage thoughtfulness and carefulness in work with older people as a basis on which well-being can be enhanced.

In the film you will hear what the members of the team who took part in the research thought about the experience of being involved. Working together was hard at times, but what we were able to achieve from doing so was so much more than would have been possible if the research had just been undertaken by academic researchers. And the benefits were experienced by all those who took part. It was a process that both contributed to well-being as well as finding out more about what this means to people.

Other sources/resources

This article describes the Fife User Panel project referred to on p.22

Barnes, M and Bennet, G (1998) 'Frail Bodies, Courageous Voices: Older People Influencing Community Care' *Health and Social Care in the Community*. vol.6, no.2, pp.102-111.

This article describes the Taste Buddies project referred to on p.22

Baur, V and Abma, T (2011) 'The Taste Buddies': participation and empowerment in a residential care home'. *Ageing and Society*, 32(6): 1055-1078.

This is the full report of the research on which these resources are based:

Ward, L, Barnes, M and Gahagan, B (2012) *Well-being in old age: findings from participatory research*, University of Brighton, Age UK Brighton and Hove.

(<http://www.brighton.ac.uk/sass/older-people-wellbeing-and-participation/>).

This is a guide produced by older members of our research team, for other older people:

As Time Goes By.....Thoughts on Well-being in Later years

(<http://www.brighton.ac.uk/sass/older-people-wellbeing-and-participation/>).

Older people's groups mentioned in these resources:

<http://www.meridian-sf.org.uk/>

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

Other work that is relevant to ethical practice in social care:

<http://www.ethox.org.uk/ethox-members/michael-dunn>

<http://www.kingsfund.org.uk/projects/point-of-care/about>

And if you want to find out more about the ethics of care you could read:

Barnes, M (2012) *Care in Everyday Life. An ethic of care in practice*, Bristol, Policy Press.