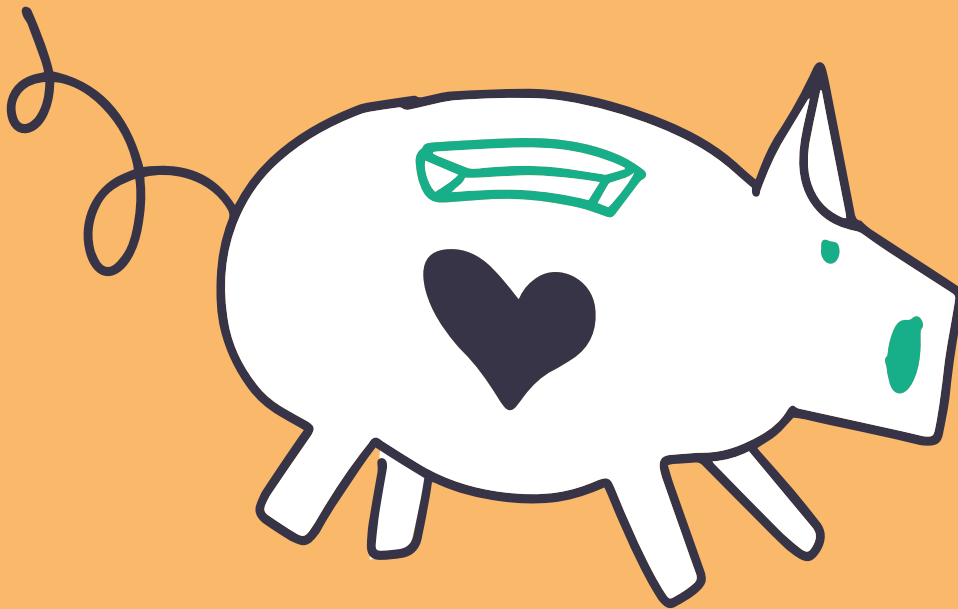




UNIVERSITY OF
BIRMINGHAM



BOOKLET

**Paying for my care
companion**

ACKNOWLEDGEMENTS

This booklet has been compiled by staff and volunteer co-researchers at the University of Brighton: Beatrice Gahagan, Bunty Bateman, Peta Brown, Marion Couldery, Jack Hazelgrove, Ursula Robson, Martin Tomlinson, Francis Tonks.

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This booklet draws on research by the University of Brighton, the University of Birmingham, and the University of Lincoln. We interviewed 65 older people who are paying for their care, along with family members who support older people with paying for their care, and a range care providers and social care professionals. The research was supported with funding from the Wellcome Trust. More information about the research is on our website <http://www.olderpeopleselffundingcare.com/> where you can find other information including Finding the Care we Want: practical tips for the journey ahead which can be read alongside this booklet.

We finished writing this booklet just before the Covid-19 pandemic hit the UK, which along with many areas of life has impacted heavily on the social care sector. Depending on where you live, this may mean local arrangements for social care have changed but your local council still has a responsibility to provide information and advice about local care services. This information should be available on your local council website. The information in this booklet was accurate at the time of publication (December 2020) but changes in the way social care is organised are expected so check with your local council for latest information.

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ABOUT THIS BOOKLET

This booklet has been compiled by staff and older co-researchers at the University of Brighton. It draws on research about what it is like to find, fund and manage care as an older person.

We have listened to the stories of older people who are self-funding their care and their family members who support them. We have included some of the things they said without revealing their identities. As some of us (the writers) are older people ourselves experiencing and dealing with some of these issues, we hope we have been able to offer some of our own insights. We have also provided some quotes from the people we spoke to about what they were experiencing.

WHO AND WHAT IS IT FOR?

Our aim is that this booklet will be a helpful resource to any older person who is either thinking about, or already paying for their own care. It offers the reader a friendly journey through some of the issues they may be confronting and the feelings and experiences that go with it.

HOW CAN IT BE USED?

It can be used as a personal resource, or to help start conversations and discussions about the subject with family, friends or carers. It also offers insights to readers of any age into some of the questions and issues that arise when finding, funding and managing care in later life.

It is not an information guide. If you are looking for more practical information about social care, we have produced a separate booklet *Finding the Care We Want* which may be helpful. This is free and available from our website <http://www.olderpeopleselffundingcare.com/>. You can also contact your local council for information about finding and funding care.

THINKING AHEAD ABOUT CARE

Thinking ahead when we are looking forward to things - a chat with a friend, a nice meal, and trip out, or maybe even a holiday- is something we all like to do. Thinking ahead when it is about planning care we may need in our old age is something we may feel less like doing. There are some difficult questions that we may put to the back of our minds, hoping we won't have to think about them any time soon:



What care will be necessary in a year, or in two, three or five years' time?

How much will it cost?

Will there be enough money to pay for it?

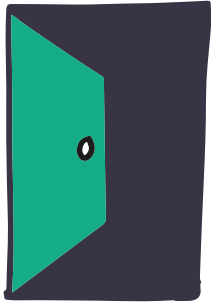
Of course, we are all different. Some of us have already made changes to our lives; others may say: "I'll deal with it when I get there." Whatever our feelings, it may be useful to consider what we can gain by 'thinking ahead'. Sometimes, we can plan ahead in simple practical ways that could make a very big difference later on. One of the older people we spoke to said:

If I hadn't found this ground floor flat and didn't live in an area where there is a good bus service, I couldn't be as independent as I am.

Thinking ahead can also allow us to take an active part in decisions about our own care, before the need arises. There may come a time when we are no longer able to participate so easily in these decisions, so there can be some real advantages in thinking about things a bit earlier than we might feel we need to.

PRACTICAL QUESTIONS

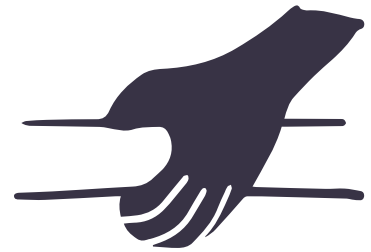
Practical questions we might want to consider when thinking ahead might include:



Should I move?



Will I need and have access to transport?



Would it make sense to have some adaptations such as a handrail, replace steps with a slope, have a walk-in shower?



Is this a good place to live when I can no longer get out and about?



Is there a bus service, are there shops, a GPs surgery?

There are many other points to review which might make life easier, not only for us, but also perhaps for our relatives and partners if we think ahead:



Have I made a will?



Do those close to me know about my financial affairs?



Have I considered legal issues such as giving someone else control over my money or health (known as 'Lasting Power of Attorney)?

THINKING AHEAD ON BEHALF OF A LOVED ONE

If you are caring for someone else, you will want to ensure you understand and meet their wishes and help them stay involved as far as possible in decisions.

They may decide to take out Lasting Power of Attorney, the legal document mentioned above. It is set up in advance as something that can be used in the future if a person loses the capacity to act for themselves. This gives a nominated person responsibility for decisions about finances and/ or care. This process must be based on a relationship of trust between the nominated person and the person on whose behalf they will act. The nominated person has to involve the person without capacity, as far as it is possible, and make decisions in their best interests.

Dementia can make this more difficult, but if you are the person responsible there are many ways of involving the person you care for in decisions that affect them, even if they cannot fully understand all aspects. One person we spoke to who was caring for a loved one with dementia said:

“Do you agree with that decision we made?”, and she’ll go, “What decision?”. But I still think it’s really important to talk it through, you know, and discuss things and, you know, I put it all in front of her, and she likes that’.

Above all, thinking ahead may sometimes involve confronting difficult questions like how long we, or our loved one, is going to live – a question that medical and care professionals may be unable or unwilling to try to answer. So, there is no perfect solution to any of these things - only learning from other people and finding our way through the best we can.

INFORMATION OVERLOAD

When we get to the point of having to make difficult decisions about our care, one of the things we need is information. In our companion booklet *Finding the Care We Want*, we have provided information that you may find useful in thinking about and planning your care needs. Relevant information about the choices and decisions we face is vital for helping us move forward. Sometimes, the need to think about and organise care can arise as a result of a crisis, possibly involving hospital admission. At such times we are likely to feel so stressed and worried by the situation that we find it difficult to take anything in.

So, the timing of what information we are given, how much and by whom is very important. We don't need too much. In fact, in a crisis we may need very little to start with – just what is going to happen next and whether the urgent things are being taken care of.

Too much information can be overwhelming – and often the first step is just to note where you might access information when you are ready for it. We hope the other booklet we have produced about finding and funding your own care will help you start to find your way through what might at first seem an overwhelming topic.



FEELINGS ABOUT PAYING FOR CARE

When you are faced with the prospect of having to spend your money on care, it can be helpful to think about the different things that money might mean to you. This will help you to be aware of its importance to you, and how feelings and decisions about money are connected to other aspects of your well-being.

We may be careful with money, not wanting to be in a position of needing to borrow from others in the future - it may be our 'safety net'. We may be uncertain about our future care needs and want to make sure we have plenty to fall back on. What is money well spent for one person may feel like an extravagance to another.

We may be reluctant to spend money on ourselves because we want to protect the future interests of our children, spouses, partners, relatives or friends. The wish to leave money to children or other relatives can be a major concern. One person said:

"I want to keep some money that I've worked so hard for, I want to give it to my children. I mean, I want that as a sort of a bit of a security blanket. That's why I don't spend it. So that I know it's there if I need it."

This person we spoke to, explained how his family encouraged him to pay for care out of his savings. But he was remembering just how hard it had been to generate savings at the time. Many people feel that their savings are their security:

"Well you should take it out of savings dad", you know ... I thought, yeah, if only you knew how difficult it was to save £100 in the old days, to see it just go out just like that ..."

We may feel we have spent a life time of paying into the public purse through taxation, with the expectation that this would see us through old age, and feel it is unfair that we to have to spend our savings on care. Another person said:

"I just feel that having paid tax all my life that I need to see some gesture on the part of the state to not make me pay again, for in tax terms for looking after myself."

Money can also be connected to our feelings of self-value and worth. We may feel that money is one thing we can offer to those we love, when our capacities to do other things for them are reduced. So, money is not a simple commodity, and there are usually deep seated and understandable reasons for our feelings about it.

FINANCIAL CONSIDERATIONS

Most people's care needs increase over time, as do the costs of care. So, there are financial considerations about how far any savings we have are likely to last. If we own our home, there may come a time when we need to consider moving into long term residential care, and if so, we might want to think about what happens to our property. There may be other people who live with us who need to stay living there, but if we live alone the financial value of our property may be taken into account as a source of funding care. We may want to approach the local council regarding financial support, and to seek out further advice about this.

One example of these kinds of financial considerations comes from a person we spoke to who was 92 and had lived in her house for the last fifty years. She felt reluctant to consider selling it in order to pay for care, but was aware that this might be something she would have to consider in the future if her savings ran out. When we spoke to her she talked about trying to limit the amount of care she was paying for to try and make the money last a bit longer:

'We bought this place when we moved from London, and I've been here on my own since my husband died in 1996... This place has a lot of memories for me, and I really don't want to leave it. I have a stair lift to help me get up and down...

I do worry about how I'm going to pay for my care...I've been drawing on my savings for some time now, and it's got to the point where I think I'll have to sell some of my shares. I've cut down on two of my lunch time (care) calls to save a bit of money, but it's not much. I have a gardener and a cleaner too, which I pay for. I don't really want to cut down any more, but I might have to one day. My daughter is very busy and I don't want to ask her for more.'

BEING A CUSTOMER OF CARE

One of the features of paying for care is that we can feel like we are supposed to behave like a 'customer' – a person who chooses and pays for things they want.

When we buy goods such as clothing, food, a fridge freezer, or services such as the work of a plumber or electrician, we know that we have the right to question, challenge or complain about what we have received if it is unsatisfactory, even if not everyone finds this easy to do.

But paying for and receiving personal care can feel very different to this. To start with, we are having to do so at a time when things have changed; we may feel vulnerable and alone.

Receiving care is also likely to impact on our sense of who we are. We may feel good about our capacity to help other people, but receiving care from others can easily lead us to feel we are of less value. It's important to remember that letting someone care for us can give them pleasure and satisfaction.

If this is our first experience of buying care, it's not always easy to know what 'good' care is: are we expecting too much - or too little? Is it reasonable to expect care to be done in a certain way? One person said:

"you'd be a fool not to see what the costs were and compare them, but I wouldn't have bought it on cost alone, by any means."

Nevertheless, some people find that paying for their care, and being a 'customer' can help to make it more empowering. One person we spoke to had lived with a disability for many years, and had no support from friends or family. She found that paying for her care meant she felt she had more control over her life:

"one of the reasons I suppose that I now pay for my care is that I feel as if I'm a bit more in control. ... sometimes in life when you pay for something you feel a bit more empowered with your voice..."

When you have problems whether they're physical, mental, emotional, psychological, it doesn't matter but when you have problems one of the most important things if you can is to keep a little bit of control because it just gives you that bit of independence, that bit of confidence and when you hand over control to people it's like you're losing a little bit of yourself really in a way.... So I suppose I'm desperate to cling onto that."

When we have found a person or company who can provide the care we need we will probably want to hang onto the arrangement and avoid having to start searching for an alternative, even if it's not providing everything that we want. One person we spoke to said:

"If I changed company obviously I'd change carers and there again it would all be new and the unknown."

And another person said:

"So they're aware of me and the thought of starting again somewhere else and having, you know, and them not knowing me at all, I don't think I could cope with that."

YOU HAVE A ROLE TO PLAY

What makes care work well often comes down to there being a good relationship between the person providing and the person receiving care. This make so much difference to both parties, so good communication is the key! As one person said:

"she's so lovely.... it's the empathy between us"

And another person said:

"...he stays a bit longer and chats about things"

It's helpful to remember that you have a very important role to play in getting the most out of the care that you are paying for. Remember that care is a two- way process, and feedback is so important for both sides. It is important to let those providing your care know how you feel if you can. At least

then they might be able to make changes in how they provide your care so that it works better for you.

Many paid carers get great pleasure from knowing they are doing a good job, and it is much more rewarding for them to know that the care they are providing for you is really helpful and making a difference.

Of course, not everyone can get along, and there may be instances where we are unhappy and need to do something about it. Unreliable care, for example, can be hugely frustrating, and can have a very big impact on other aspects of our life.

For example, if you need someone to help you get ready in the morning and they are late - this could lead to missing an appointment or a trip out. As one person explained to their carers:

'I said can you please make sure that my timeslot never changes because I know it's difficult when somebody's got, you know, 4 carers a day but mine, because mine's one slot, because there are other things I do.'

It is good to know who to call if you need to make a complaint and one mark of a good care provider is whether they make it clear how you can contact them if you are unhappy with your care. They should also seek opportunities to get your views on the care you receive from time to time.

"they come personally and go through a little questionnaire but I'm very satisfied with them, there's no problem"

Whatever the case, it is important to remember the role you can play, in shaping the way care is given.

PREPARING FOR CARE VISITS

Being clear about what you want and need is a key ingredient in the task of preparing for care visits. At first this may be the opposite of what you expect, but many people find there is a certain amount of 'work' involved in receiving care. As one person said:

"once you ... tell them...they're perfectly happy to do just what you want to do"

And another said:

"I have to sort of try to make it known that it just doesn't suit me"

Getting older requires lots of adjustments including how we do things, and how we problem solve the challenges of daily life. When you are waiting for a carer's visit, there may well be a list of things that you need them to do. Being dependent on someone to do as many things as possible in the time they are with you requires making of note of the things that have cropped up since the last visit - such as finding the telephone book that dropped down the back of the sofa, or checking that the window is locked properly.

'I have to have that plan and I have to have the detail of that and I have to know where everything is and tell them where this is and that'

FAMILIES, SOCIAL RELATIONSHIPS AND CARE

Family relationships are often complex and just as it can be hard to receive care from sons or daughters or those close to you, equally it can be difficult for family members to accept a new role in relation to their loved one.

Often it is more of a challenge because of the closeness of the relationship. An older parent who has lost independence and now needs care, may be changing his or her role from a life-long care-giver to a care-receiver.

Relationships inevitably change and there can be tensions. Existing patterns or problems in family relationships are likely to become more evident when placed under strain. One person said:

"My children had to step in last year with trying to organise a lot of things for me but now I've kind of taken that back again which I had to do quite carefully."

Not everybody has the skills or confidence to deal with all the different tasks that can be involved: managing finances, personal care or nursing. Some people are uncomfortable providing or receiving personal care from those they love and having someone independent who is not a relative makes it easier to remain objective.

This person, aged 91, and widowed for over 30 years reflected on the relationships in her family. Although health problems meant she needed care herself, she continued to feel she had ongoing responsibility for them and did not approach them or depend on them for support.

... if you live in a family where you always ask things, they will do a lot more. I have never asked for anything and there are not a lot of offers from the family. But it suits me... we have never really switched from she is looking after us, now we look after her. We haven't ever got there.

On the other hand, for others the opposite is true and providing care or receiving care from a loved one can enhance the relationship in unexpected ways.

Whatever the case, we must respect that changes in health and independence bring challenges to all

kinds of relationships, and if someone is unwilling to do something, or to receive something, it does not necessarily mean that they don't care. One person said:

"My daughter down here... she was trying to control me, as I said, and I wouldn't have that. My other daughter, she said 'mum, you have whatever you want, you spend it, you've earned it, do whatever you want with your money'. My son, he sits on the fence! "

RESILIENCE

We know that ageing happens to all of us lucky enough to live a long time. Some of the things associated with ageing, such as having to rely on others, are not easy. On the other hand, living a long time means we have more experience of coping with life's ups and downs, and more ways of being resilient in the face of life's' challenges. It can give us a greater sense of perspective.

One person when talking about her carer said:

I've never resented them being in my home at all or, you know, doing things their way. Yes, sometimes I am astonished, I think, oh my God, I hope your mother doesn't do it like that, but apart from that, you know, it doesn't bother me.

And another said:

I'm not, I'm not sad at all, I'm very positive, I feel I've got to be now, I've got to make the best of my life, what's left, I'm 87 so I don't think I'll live to be 100!

The next section is written directly by two older members of our research team. They thought it might help others to know a bit about their own thoughts and experiences. You are not alone!

FOOT NOTES WRITTEN BY OLDER CO-RESEARCHERS



1. A foot note on how local people can be a source of help

I was an active member of the group which undertook this research from its inception. But at the age of 83 I had a stroke which put me out of action for a year. On my return to the group I was asked to read the draft of this booklet. I was astonished at how closely the findings accorded with my own experiences. In particular, I have developed a very close relationship with my daily helper who comes to assist me with personal and household tasks. Similarly, an especially reliable and helpful taxi driver who takes advanced bookings has given me his personal contact number. We have also become friends and he enables me to continue my life with a degree of independence. Otherwise I manage alone with the support of my family and friends who are loving and willing, but I am anxious not to impinge too much on their own busy lives.

Two other aspects which chimed for me were 1) the need to plan before the carer arrives, so that essentials are remembered and 2) the importance of keeping to time in order that you can continue with other plans for the day.

I was surprised that what does not seem to have emerged from the research is the help that can be obtained using technology from local social media resources such as face book. It was via this route that I found both my daily helper and my taxi driver, among other things. I would recommend this as a source of help although it does mean you have to become more personally involved than using an agency.



2. A foot note on 'looking forward'

As we get older we can have a tendency to spend time thinking of the past. We may be luckily enough to have family or friends with whom we can share memories but even on our own we can feel a warmth and pleasure remembering past events and loved ones. However, dwelling on past events or being overly nostalgic may cause us to feel a sense of dissatisfaction; comparing what was with our present lives. Looking forward can also give pleasure and enhance the quality of our lives.

Whatever age we are, we all need this strategy - 'Looking forward'. Surprisingly even our dull days pass more quickly if something good is happening tomorrow

For the more fortunate this may be a holiday, an outing with a friend, attending a luncheon club or a social cup of tea. If however, mobility problems or other issues prevent such events we can derive pleasure from small things ... a weekly phone call to a friend; a TV programme we enjoy - perhaps with a special treat; a favourite meal or a few chocolates.

A phone call to a local organisation could also improve our situation. This may seem daunting, almost impossible for some, however there are many volunteers offering befriending and a call could make this possible. Then one could look forward to a regular visit from a new friend.

Being old does not preclude us from looking forward and finding pleasure in tomorrow; as today's pleasures are tomorrow's good memories.



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