



UNIVERSITY OF
BIRMINGHAM



BOOKLET

Finding the care we want

Practical tips for the journey ahead

ACKNOWLEDGEMENTS

This booklet has been compiled by staff and volunteer co-researchers:

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ABOUT THIS BOOKLET

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 of 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 The Paying For My Care Companion which can be read alongside this booklet. Both booklets were co-written by older co-researchers who worked on the research alongside the academic teams.

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 will provide information and advice about local care services and this should be available on their 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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INTRODUCTION

Many older people have to arrange care for themselves or for a relative or friend, either at home or in a care home. While we may expect to receive treatment on the NHS free of charge, it can come as a surprise to find that social care is not funded this way and that you may have to pay for some or all of your care.

Finding and paying for the right care at the right time can be a daunting prospect. The older people we spoke to sometimes found the process frustrating and confusing. We hope that the information contained in this booklet will help you find a way to get the care you want and need.

Everybody's circumstances and needs are different, and the regulations governing social care are subject to change both locally and nationally. We don't offer any definitive advice except perhaps to make contact with your local authority's adult social care team as early as possible. They have a responsibility to provide information and advice about care services and the regulations about who pays for what. The latest information should be available on your local council website and your local Age UK or Citizens Advice Bureau may also be able to offer advice and information.

WHO IS THIS BOOKLET FOR?

This booklet is for older people who are thinking about arranging care for themselves or someone they know. It is primarily aimed at people who are thinking of arranging care in their own home. We hope that it will help you ask the right questions when you are looking for a service to meet your needs. By having a few useful questions in mind and a little information we hope you will be in a better position to get the care you want.

At the end of the booklet we have included a glossary of some of the terms, jargon and abbreviations often used by social care professionals and care providers.

WHAT IS MEANT BY 'CARE'

In this booklet by 'care' we mean any service that is paid for and is provided in your own home to help you do the things you would normally like to do, and to keep you safe and well. Everyone's needs are different, and can change over time, but 'care' can include things like help with washing and dressing, getting into or out of bed, meals or shopping, or some forms of housework, and getting out and about.

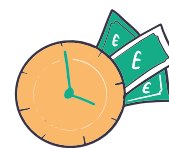


WHO PROVIDES CARE?

In the past, most care in people's homes was provided by their local authority, which employed its own care workers (sometimes called home helps). Care is now usually provided by private companies and sometimes by charities. There are many such care agencies, some large and national, some small and local. Organisations that are registered with the Care Quality Commission (CQC) in England are inspected and must meet certain standards. Their inspection reports are published online. Many care providers advertise online or in the local press. Some charities such as Alzheimer's Society and The Carers' Trust may also be able to help. Sometimes individuals, or even friends may provide care and while these might offer a more personalised service at a more economical rate than many agencies they may not be regulated by inspection or fully trained and insured.



WHEN MIGHT I NEED CARE?



This is a difficult question to answer, as everybody's circumstances are different. Some people find they need to arrange care after a spell in hospital, others because they are aware they are finding it harder to do the things they would normally do.

DOES NEEDING CARE MEAN GOING INTO A CARE HOME?



Not necessarily. Most people who pay for care choose to have it provided in their own home. Many types of care can be provided at home, up to and including some forms of care that once would have been provided by district nurses. For others, perhaps who need more intensive forms of help, a residential or a nursing home could be a better option. There are also new housing developments known as Extra Care or Assisted Living. These offer accommodation to buy or rent within a complex of similar properties with shared facilities and for care services to be provided in different ways according to your needs and wishes.

HOW MUCH WILL IT COST?



Care provided by a care agency in your own home could cost anything between £15 and £27 an hour for weekdays (prices approximate as of early 2020). Weekends and bank holidays are likely to be more expensive, and in some areas, particularly rural ones, there might be an additional mileage charge. Care in a residential home or nursing home could cost a lot more not only because of the costs of the buildings and maintenance but because of the extra services provided, such as twenty four hour staffing, all meals and domestic services, and in some cases medical care.

WHAT IF I WANT TO PAY A FAMILY MEMBER, FRIEND OR NEIGHBOUR TO PROVIDE CARE?

It is possible to employ a member of your family, including someone living in the same household, as a carer, but some people prefer to pay an individual outside the family who is known to them or is recommended to them. This arrangement can sometimes work out well and provide flexible care and value for money, but some people might not be comfortable with certain tasks such as personal care, or have the appropriate training and skills.

A registered care agency should have staff trained to help with a wide range of needs and will have checked their carers' references and have safeguarding procedures in place. A care agency should also be able to provide a carer for you if your regular carer is not available, whereas your friend or neighbour might not be able to do this.



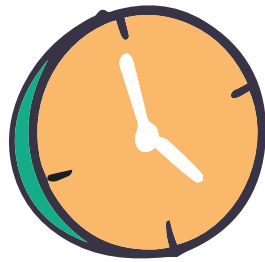
WHAT CAN I EXPECT WHEN PAYING FOR CARE?

Most good care agencies will do their best to meet your needs and as their 'customer' you might expect to get the care you want, when you want it. But it is also true that most care agencies struggle to recruit carers and may not have the capacity to meet your needs exactly. Care workers are often under pressure and may have a limited amount of time to spend with you. Sometimes, the nature of the work they do – helping people in need – makes it hard to always be on time.

As a minimum you can expect to know:



How many hours of care will be provided



When the care worker will arrive



What your care worker will do while they are with you



Who to contact should there be any last minute changes on either side.

A care agency should provide a contract in writing that will specify the details of your agreement, including information about fees and invoicing and what they will do if your carer can't come through illness or holiday. It's worth taking time to read this contract carefully and to ask questions if you aren't clear.

You can expect to have an opportunity to discuss arrangements personally with a senior representative of the care agency before agreeing to anything, and possibly to meet at least one of your care workers. There are other things you can do to help develop a good working relationship:



Before your first meeting with a representative of a care agency it can be useful to write down any questions you want to ask. Don't be afraid to ask 'silly' questions – they rarely are! It might be a good idea to have someone with you for support and to help remember what is said.



Prepare to answer questions about what you need help with.

Be honest and open and give as much information as you can about your needs.



Often it is the little things that make a difference to the quality of care we receive.

It can be helpful to make a list of your preferences such as how you like your tea, whether you use soap on your face etc. Other things such as allergies and health needs should also be noted.



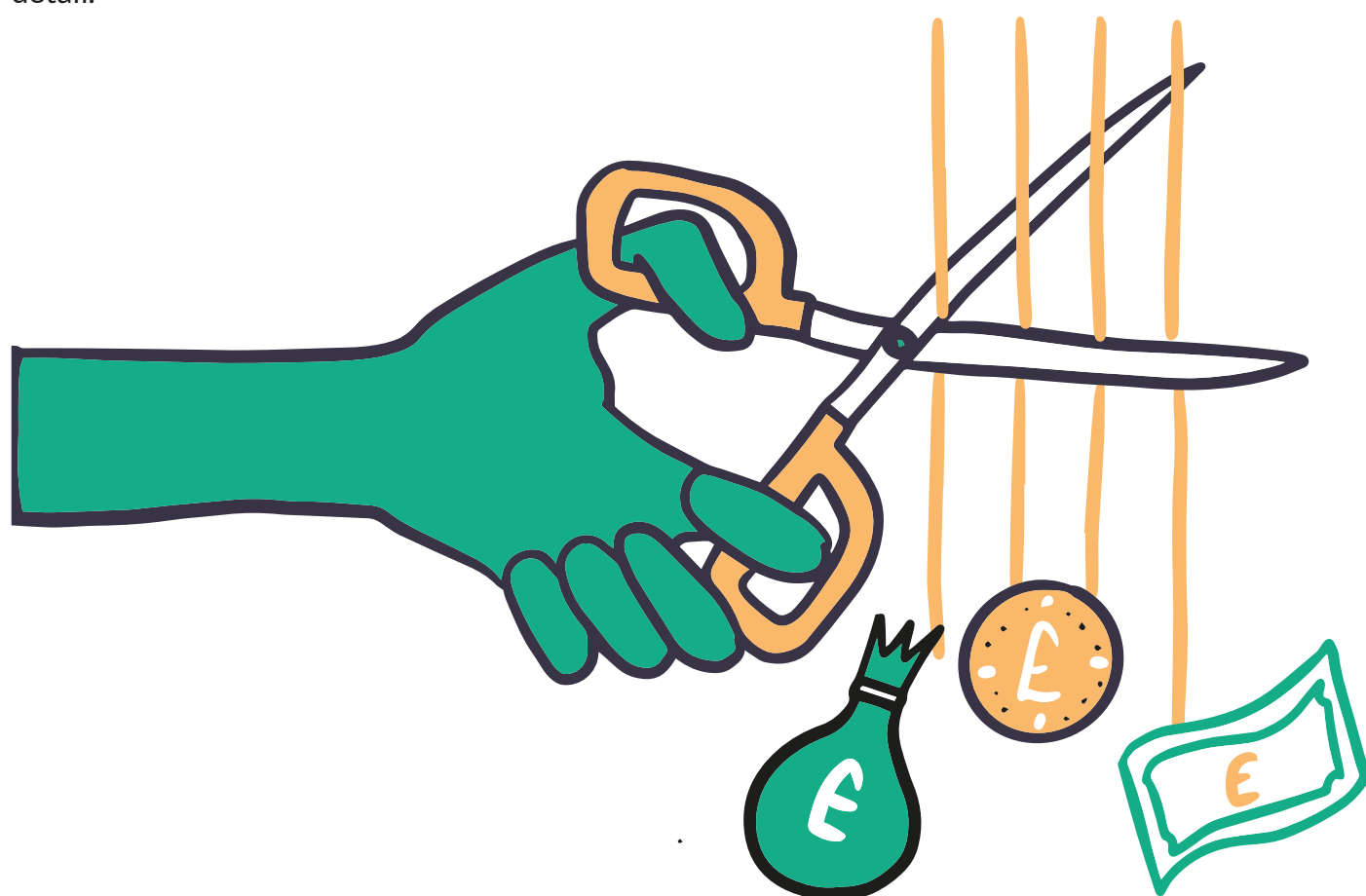
Over time you might get to know your carers well,

but it can be useful to label things like cupboards and drawers to show where essential items are kept, particularly if you have different care workers coming in at different times.

CAN THE LOCAL AUTHORITY HELP WITH THE COST OF MY CARE?

Many people are surprised to find that care services, unlike medical services under the NHS, are not always free at the point of use. In general, only people who are on low incomes or do not have savings or extra property may be entitled to local authority care. Currently, if you have property other than your own home, or savings or income worth over a certain amount then you are unlikely to be entitled to any help with the cost of care.¹ If your assets fall below the threshold, then the local authority may pay for part or all of your care, depending on their assessment of your needs and finances. If your medical needs are complex, or if you are just out of hospital, you may be eligible for some free help at home through NHS 'Re-ablement' or 'Continuing Health Care' schemes.

The regulations about who pays for care are complex and subject to some local variation and change. It's a good idea to get up to date information from your local authority or a branch of Age UK. The 'Which? Guide to Local Authority Funding for Home Care' also describes the regulations in more detail.²



¹ For up to date information please contact your local authority or visit <https://www.nhs.uk/conditions/social-care-and-support-guide/help-from-social-services-and-charities/financial-assessment-means-test/>

² <https://www.which.co.uk/older-life-care/financing-care/home-care-finance/local-authority-funding-for-home-care-a116w2u6nbul>

IF I OWN MY OWN HOME, WILL I HAVE TO SELL IT TO PAY FOR MY CARE?

Many people worry about this. The short answer is that if you own your own home and are living in it there is no obligation to sell it to pay for care. If you go into residential or nursing care the value of your home can be taken into account as part of your assets. However, if your partner, or in certain circumstances a relative, remains living there, the value of your home may not be taken into account until the property is sold. Again, it is a good idea to get advice from your local authority or your local Age UK or Citizens' Advice Bureau.



DO I NEED TO TELL THE LOCAL AUTHORITY IF I NEED CARE?

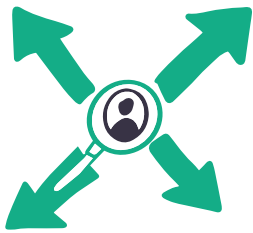
Not necessarily. Some people choose to by-pass the local authority altogether when finding and arranging their care. But anyone who appears to need care and support is entitled to a free assessment of their needs and financial resources by the local authority. There may be a waiting list for an assessment and the assessor will need to know details of your care needs and the resources you have available to meet them. An assessment by the local authority is confidential and you do not have to act upon its recommendations. Even if you are not eligible to have some or all of your care and support needs met by the local authority at that time, having an assessment can be helpful as it may help to identify what sort of help might meet your needs. This can make things easier if at a later date you need to approach the local authority again, for example, if your financial assets reduce.

WHAT IS GOOD CARE ANYWAY?

Some people might say that it's one of those things you know when you see it. You should expect to feel cared about as well as cared for. When you reach an agreement with a care agency there are some things that might help you judge whether the care is likely to be of good quality. Often what makes the difference is down to your own tastes and feelings. But here are a few questions that might help you make a decision:



Does the care agency make an effort to understand your needs and those of your family? Do they appear to listen?



Is it clear who is responsible for what? This includes responsibilities for providing information, sending accurate invoices, for care workers turning up on time and for supervising the quality of care that is provided.



How well trained are the care workers? How does the agency keep up to date with training? Do the staff seem happy in their jobs?



How flexible is the care agency should you need to make changes, possibly at short notice? How do you go about making changes, and what will the care agency do if they need to make a change? Will they make a charge for changes made at short notice?



What form of review does the agency take of your care service and how are you involved in it?



Are you entitled to a trial period to make sure the service meets your needs?



Can you have a say in which care workers you have?

GLOSSARY OF TERMS

Like any industry, business or profession, care services may use a number of terms which might not be familiar to everyone in the first instance. Here are just a few in alphabetical order.

Adult Social Care: A general term for social services and disability assistance provided by local councils, private and charitable organisations, but often used to describe a team of people employed by the local council.

Cancer care: Specialised care for cancer patients. May be provided by local community groups, private companies or national organisations and charities such as MacMillan Cancer Support.

Care Agency: A company that provides care services, sometimes on behalf of the Local Authority (Social Services). Some care agencies might be part of national or even international companies, while others might be local franchises or small private companies serving a local area or clients with particular types of needs.

Carer: This is one of those terms that can mean many things. It can mean a friend, relative or spouse who provides care to someone without charging for it. Often such a person is called an **Informal or Unpaid Carer**. Staff who are employed by a care agency to provide care in your own home or in a residential setting may also be called carers. In this booklet we use the term **Care Worker** to distinguish them from informal carers. They might also be known by such terms as **'Personal Assistant,' 'Home Help' or 'Domiciliary Care Worker'**.

Care Quality Commission (CQC): The independent regulator of health and adult social care services in England. Their job is to ensure health and social care services provide people with high-quality care and to encourage care services to improve. The regulator in Wales is the 'Care and Social Services Inspectorate'; in NI it is the 'Regulation and Quality Improvement Authority' and in Scotland the 'Care Inspectorate' comes under 'Healthcare Improvement Scotland'.

Continuing Health Care: NHS Continuing Health Care is for people with complex, unpredictable and intense care needs. It is not means tested (unlike Social Care) and needs are met and/or paid for by the NHS. Decisions are based upon detailed assessment of need and are reviewed periodically.

Dementia care: Specialized care for people with dementia. May be provided by local community groups, private companies or national organisations such as the Alzheimer’s Society.

Deprivation of Capital: This is a term used by local authorities to describe an action taken by an individual or their family to deliberately reduce a person’s capital in order to obtain means-tested benefits, including payments for social care.

Domestic help: Help with gardening, cooking, cleaning, shopping, driving etc.

Domiciliary care: Care work that happens at home

Extra Care housing: Self-contained housing with helpful design features and extra services such as a café or restaurant. A dedicated care team is usually on site.

End of life care: This type of care is usually available for those who are expected to die within 12 weeks, and may be provided, or funded by the local council.

Independent Living: This can refer to various specialist housing approaches for people with disabilities that are tailored to individual needs. Sometimes these are referred to as Independent Supported Living. The term can also refer to a residential facility in which people, usually aged 55 or over, buy, rent or lease a property within a complex that may include facilities such as a restaurant, hair and beauty salon, activity studio or a gym. Some will also provide care services, or you may ‘buy in’ your own.

Lasting Power of Attorney: A Lasting Power of Attorney (LPA) is a legal document that allows any nominated person to take care of another person’s affairs, including their finances, should they become unable to do so themselves. There are two types of LPA: a “Property and Financial Affairs LPA”, which covers paying bills, managing a bank account or buying or selling property, and a “Health and Welfare” LPA, which covers decisions about health and care and even deciding where someone is to live. An LPA can only be used if someone is incapable of dealing with such matters themselves, and is intended to ensure that their affairs are handled correctly and quickly. See <https://www.gov.uk/power-of-attorney> for more information.

Local authority: Larger Councils, such as County Councils and Metropolitan or Unitary authorities that are responsible for local social care services, advice and information and will have a team of

people concerned with 'Adult Social Care'.

Life-Line or Emergency Call Service: Help available over the phone, usually triggered by pressing a button on a pendant, bracelet or wrist strap.

Live-in care: Where someone comes to live in your home with you. Various arrangements can range from a helper simply cooking an evening meal and being there at night, to care workers providing cover at all times.

Medical or health care: Provided by doctors, nurses and other professionals, through the NHS, or private medical companies to meet a wide range of medical needs.

Nursing home: Care provided to residents in a home specialising in the needs of people who need a substantial amount of help including medical help from qualified nursing staff.

Palliative care: Care provided to manage symptoms when there is no cure available for your health condition.

Personal care: Help with washing, dressing, toileting, taking medicines and personal hygiene.

Re-ablement: This is a type of care that focusses on helping you regain some of your own abilities. It may be provided in your own home, or at a residential reablement centre and is provided or contracted by the local authority for a specific period of time, usually a few weeks to help you maintain or learn skills that will help you live independently. How much and what form of re-ablement is right for you will depend on your needs and circumstances. Usually it is provided free of charge following a period in hospital.

Residential care: Care provided to residents living in a care home or in specialised housing.

Respite care: A temporary stay in a care home or hospice, to give families and older people a break from managing their care at home.

Sleep-in care: Where someone comes to stay with you overnight. This might be more temporary than live-in care.

Social Care: A general term for a range of services to people who need help with various aspects of their daily lives through old age, disability or illness. Local Authorities have a duty to provide a certain level of Social Care under certain circumstances, but it is usually delivered by a wide range of public, private and voluntary organisations. Social care may be paid for by the local authority or may be paid for privately, or a combination of these.

Other Possible Forms of Help

Food: some local outlets such as supermarkets and shops, may deliver ready-made-meals, which can be ordered either by telephone or online.

Aids and Gadgets: There's a huge range of products and 'assistive technology' available – everything from stair-lifts, step-in showers and reclining chairs to key safes, pill dispensers and easy-to read reminder clocks.

Fire safety: Your local fire service can provide safety advice and fit smoke alarms - often at minimum or no cost.

Waste & recycling: Your local Council may be able to provide help putting your bins out.

Getting out: There may be local community transport schemes that will enable you to get out and about; and local clubs and organisations that can offer companionship and support. A wide range of mobility scooters are available too.

Independent Financial Advice: There are many sources of financial advice. Some, such as the Society of Later Life Advisors (SOLLA) have expertise in the needs of older people and care.

Online help: You can find advice, support details of local groups through Age UK at <https://www.ageuk.org.uk/>. Comprehensive information, advice and practical guidance about care in the UK is available free from <https://www.which.co.uk/older-life-care>



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