

1 Exploring other options

Most older people – or their relatives – consider residential care only after a crisis. They may have broken a bone, or gone out and left the gas on. A care home is NOT automatically the answer. In this chapter, we explore your many options, from getting more help at home, to moving to more suitable accommodation.

Short-term therapy after a hospital stay

Once you no longer need ‘acute’ medical care, you have no legal right to stay in hospital. If you need more time to recover, ask about a **reablement** or **rehabilitation** programme. A team of NHS staff works with you in a community hospital ward or in your own home to get you well enough again to manage independently.



“Medics tend to err on the side of caution and suggest a nursing home. Social workers like me explore what led to the broken hip or the gas left on and try to find solutions, remembering you can’t take all risk out of older people’s lives.”

Gary, social worker

Care at home after a hospital stay

You may be well enough to go home but still need a lot of help. The hospital social work team should assess you and provide any basic equipment you need such as a toilet-surround frame, crutches or a shower seat. If you need carers to help you wash, dress and use the loo or commode, you may have to pay for them. Read our factsheet: Hospital Care in England: everything you need to know before, during and after your stay . Chapter 8 of our Wise Guide, Extra Help at Home is also packed with useful information (or call us for advice on 0800 319 6789).



If services are arranged for you when you leave hospital, ask who's going to visit, how to contact them in an emergency and if you have to pay.

Simple gadgets and alarms to make you safer

There are gadgets to ensure you don't leave the gas on or let the bath overflow. There are also alarm buttons and sensors you can wear to call for help or detect a fall. All can be bought privately. Or phone social services (in the phone book under your council) and ask for a telecare needs assessment.

Read our factsheet: Telecare and telehealth: what it is and where to get it (or speak to an expert adviser on 0800 319 6789).

Adapting your home to make it safer

It is usually far cheaper to adapt your home, perhaps by installing a walk-in shower, than go into a care home. Read our factsheet: Adapting your home to stay independent (or call us for advice on 0800 319 6789).

A live-in companion

There are schemes which match you with a responsible younger person who lives with you rent-free in exchange for company, light housework and help with bills, meals and shopping. They will not usually be able to help you with personal care tasks like getting washed and dressed.

sharedlivesplus.org.uk/homeshare (Bristol, Cumbria, East Sussex, Somerset and London)

roomfortea.com (London) on 0203 239 4913

Moving in with family

This can work well if you think ahead:

- are you expecting your relatives to look after you or has care been arranged?
- is there a downstairs loo, adapted area or 'granny flat'?
- will noisy toddlers or teenagers drive you crazy?
- will you feel lonely when the family is out at work or at school?
- who will pay which bills?
- take independent legal and financial advice if you plan to contribute to buying a bigger house for you all. Who will pay if you later need residential care?



David's story

"Dad's dementia got worse after Mum died. We tried organising carers to come in but it just didn't work with him living so far away. My wife felt he should live with us but I wasn't sure. We were in our 40s, both working full-time, with two awkward teenagers and a ten-year old.

"By selling our home and Dad's, we were able to afford a new house where Dad – and his dog - had a garden flat with separate front door. I'm an only son so there were no inheritance problems.

"It wasn't easy. Dad would want breakfast at 4am. He'd go to the wrong house and demand entry. One Christmas Day, I lost my temper and felt like smacking the children and him. We coped by employing lots of help, like a kind woman carer who'd take Dad to concerts.

"Dad died at home two years after we moved. He never went into a home - except for two weeks' respite care each summer to allow us to take a family holiday."

Live-in care

Live-in care could be something to consider if you find that you need a lot of support. It means having personal carers that live in your home, 24 hours a day. A live-in carer can help with things like:

- your personal care
- managing your medication
- moving around the house safely
- shopping and cooking
- getting out and about.

This can be an expensive option, but means that you can stay in your own home and may not be any more expensive than having to pay care fees in a care home. You can find details of agencies offering live-in care through the United Kingdom Homecare Association (ukhca.co.uk, 020 8661 8188).

Day care at a centre or hospital

Exhausted caring for a partner with dementia? Ask your social services about day care services or contact Alzheimer's Society (0300 222 11 22, alzheimers.org.uk) or Dementia UK (0845 257 9406, dementiauk.org) for advice and support. Alzheimer's Society has a good factsheet, *Respite care* .

A move to more suitable housing

One solution is simply to move to more suitable housing. **Sheltered housing schemes** - also called 'supported housing' - have some shared facilities such as a lounge and laundry, a non-resident warden and sometimes also a built-in emergency alarm, grab rails in the bathroom and non-slip floors. You have privacy and independence but also reassurance and company.

Extra care schemes – have all the facilities of sheltered housing with on-site care staff during the day and sometimes also at night.

Retirement villages – have various types of housing – perhaps including a care home – on one site. A good choice if you don't want to move, then have to move again.

The Elderly Accommodation Counsel (0800 377 70 70, firststopcareadvice.org.uk) can provide a list of available housing in your area.



“Think ahead. We found the ideal extra-care scheme for Mum and she was keen but they had a long waiting list.”

Diane, 65

Advice for council and housing association tenants

Contact your housing office and ask about exchanges, transfers and rentable sheltered housing.

There are many and cheaper options to residential care. To help you work out what to do next, we recommend you have a ‘care needs assessment’ (see chapter 3).

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2 Moving into a home?

Going into a care home offers many benefits – security, peace of mind and companionship. However, no one leaves their own home for a care home without a great deal of soul-searching. If you are paying your own fees, you'll also need to consider the expense. The national average weekly cost for residential care in England is £550, and for nursing home care, £728. (Figures taken from Care of Older People UK Market Survey 2013/14, Laing & Buisson, 26th edition)

It may be time to think about full-time care when:

- you need a great deal of care – by day and crucially, also during the night
- your need for support or supervision can no longer be met in your own home
- you have explored every other option (see chapter 1)

The benefits of residential care

If your memory is failing or you get confused in time or place, you can benefit from the structured routine of a care home. Eg, if you have a fading memory and smell food cooking or see fellow residents filing into the dining room, you may remember that it's lunchtime.



“Auntie used to spend all day in bed and would throw away the meals we made her. We couldn't believe the transformation when she moved into the home. She dressed for dinner and played bridge with the woman in the room next door! We realised she must have felt very lonely and depressed.”

Janice, 58



Did you know...The health of older people who have been living

alone and not looking after themselves usually improves on entering a care home.



Did you know...the risk of Alzheimer's disease more than doubles in lonely older people.

Purpose for life and stimulation

Some older people find new responsibilities and worthwhile jobs to do in a residential home whereas alone, in their own home, they felt depressed, bored, lonely and unwanted.

Variety and expertise

A person being looked after by a relative sees the same face every day and the care is only as good as that individual can provide. In a residential care home, you benefit from the stimulation and variety of meeting several different people. They are experts in looking after older people, experienced at looking after people with dementia and skilled at different therapies. They know where to find specialists able to provide customised services such as therapeutic massage, hydrotherapy, and footcare (podiatry or chiropody).

Specialised equipment

A home will have customised equipment throughout such as grab rails, hoists and stairlifts. If you are very disabled, there may be a limit as to how much you can adapt your own home and it takes time, money and effort to effect alterations. Plus you may need the equipment urgently. However, if lack of equipment is all that is preventing you from staying in your own home, ask for help. Contact your council, phone

Independent Age on 0800 319 6789 or read our factsheet: Adapting your home to stay independent .

Taking pressure off your family

Even the most loving family can find the full-time care of a relative very demanding. This can lead to friction within marriages and between siblings. Small children may not understand why their granny or granddad takes up so much of Dad's time or why Mum is short-tempered. Your relative may feel tired and stressed looking after you; in a residential home, the caring role is shared and your family can still come in and help.



Rose and Jim's story

Jim, 78, had dementia. As his wife, Rose, 80, became less mobile, needing a Zimmer frame to get about, she found it harder to look after him. A perfectionist with high standards, she found it frustrating trying to keep her husband presentable and he began to sense her annoyance.

The day centre care workers noticed Jim's agitated state when he arrived. He'd settle down but became stressed when it was time to return to Rose. The happily-married couple were no longer getting on - Jim sensing his wife's displeasure, Rose frightened at her husband's aggression.

For two months, on their social worker's suggestion, they had carers in three times a day to help Rose while Jim continued to attend the day centre. It didn't work. Jim was even more disorientated seeing so many new faces, and it didn't suit their early-rising lifestyle either. Jim was usually dressed by the time his carer arrived to help him shower.

So their social worker suggested Jim try a care home for a month - with his wife visiting three times a week. He continued going to the day centre and came home for Sunday lunch with the family. This worked much better. Jim was much less aggressive because he wasn't stressed. After a month, Jim and his family decided he

was happier in the home with Rose visiting, than in his own home. Rose was happier, too, though she missed Jim.



“I am registered blind and have a rare blood condition. I often need help at night which is more than my daughter could manage. The place we found is very friendly. I have my own room with my own furniture and a bell I can ring, day or night for help. I have breakfast in my room and lunch and dinner in the dining room with the other residents. I’ve joined a local Blind Club and go on outings with them, and it’s near enough for my daughters to visit often. It’s not my own home but pretty near it and I feel safe and cared for.” Jean, 88



Did you know...if you’re not sure if going into a care home is for you, you can try it. Ask for a temporary care place or say you’d like to try it out before you commit yourself.

Decided a care home may be the best option? The next step is to get a professional’s opinion known as a ‘care needs assessment’ especially if you’re going to need help to pay the fees.

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3 Calling in the experts

In chapter 1 , we looked at options that don't involve going into a home. Still not sure what to do next? Now's the time to call in the professionals to see how much help or nursing you need. Expert advice is free and you don't have to do anything you don't want.

What is a 'care needs assessment'?

Think of it as a 'look see'. Professionals from social services who deal with older people every day can come and see how you are managing – or not – at home and make helpful recommendations. They'll:

- look at what you can and can't do, such as seeing whether you can make use of your home safely and take care of your personal hygiene
- ask you about your health and any difficulties
- ask the opinion of people who see you regularly such as your family, GP, occupational therapist or community nurse
- assess your wellbeing and whether your care needs are affecting this
- see what equipment you're using, if any
- see what else they can provide to keep you as independent as possible.

If you think you need to go into a care home, the professional will also:

- assess your psychological, emotional and social needs such as your wish to be near family and friends
- assess your religious, spiritual, cultural and communication needs such as your wish to attend Mass on Sundays.



Did you know...

- asking for a care needs assessment DOESN'T mean the next step is a care home. The professional you speak to may decide you're NOT vulnerable enough for the council to recommend residential care
- staying in care homes is expensive. No one is pushing you into this - the council must take your preference of accommodation into account. If you need support to express what help you need and don't have a friend or relative to support you, ask the council about local independent advocates. They can support you to communicate your wishes and concerns
- if you have full mental capacity to make your own decisions, even if the council recommends you move into a care home, you may refuse. You have the right to remain at home even if this puts you at risk physically.

If you do want to move into a care home but the council recommends that you stay in your home with a care package, you can ask for a review of your care needs to make sure that the assessment has taken full account of all the difficulties and risks you are experiencing at home. A family member or friend can represent you to ensure your problems are properly recorded- eg, frequent falls, forgetting to take your medication or turn off gas and electricity, loneliness or anxiety. You can also make an official complaint to the council if you disagree with the decision after a review.

If you need support to express what help you need and don't have a friend or relative to support you, ask the council about local independent advocates. They can support you to communicate your wishes and concerns.

How to arrange a care needs assessment at home

Contact the social services or adult social care department of your local council. Your council's number is in the phone book, council offices, library, GP's surgery or on the local government website for your area.

For more information about how needs assessments work, read our factsheet: [Assessment and services from your local council in England](#) (or call us on 0800 319 6789).



Silvija's story

After Silvija had a couple of falls, her niece became anxious about her and thought she should go into a home. But the social worker who came to assess Silvija's care needs felt this was premature. He made various suggestions: she could get a community alarm or join a scheme like Homeshare where a younger person lives rent-free or at a reduced rent with an older person in exchange for light housework, cooking and shopping.

He also recommended referral to a falls clinic and installing grab rails in the bathroom and on the stairs. Another option was to move to sheltered housing nearby. The social worker gave Silvija a list of suitable housing to think about and recommended she go on the waiting list even if she hadn't made up her mind.

Part of the care needs assessment – do you need nursing, and if so, how much?

Nursing care can only be carried out by a person with medical training and experience such as a registered nurse.

Assessed as needing a nursing home?

A medical professional will assess you separately and decide if you qualify for the NHS funded nursing care (NHS FNC) - a payment towards the nursing element of your care fees in a nursing home. As of April 2015, this amount is £110.89 a week, but this amount may be reviewed later in the year.

Need a lot of medical intervention, rather than just personal care?

If necessary, a medical professional will assess you for fully-funded NHS continuing healthcare. Only people with the most complex healthcare needs qualify; you have to be poorly enough to require hospital-type equipment, support and treatment. If you are eligible, everything - your nursing, bed, board and personal care - in a home will be paid for. Search 'NHS continuing healthcare' on the [NHS Choices website](#) or

read our factsheet: Continuing healthcare – should the NHS be paying for your care?
or call our expert advisers on 0800 319 6789.



Think you might move to a care home outside your area, to be nearer family or friends? Make sure the assessor notes this in your written assessment NOW as a NEED. If you don't, your council may consider you moved out of preference, not need. If the home in the new area is more expensive, they may not offer to cover the full fees.

The financial assessment. Will the council pay for you? (more in chapter 5)

After the care needs assessment, there's a financial assessment. The council will decide:

- if they will provide support for you
- if you can afford to pay the fees yourself
- if you qualify for any financial help from the council.

You'll be asked what savings and income you have and what benefits you are claiming. You will be asked if you own any property. The council:

- is not allowed to ask your spouse, civil partner or partner about their income and savings
- must ignore half of your occupational pension or income from a retirement annuity if you give it to your spouse or civil partner to help support them at home.

Assessing finances is complicated. Read more in our factsheet: Care home fees – paying them in England .

If you live in Scotland, Wales or Northern Ireland, the way the assessments work and your finances are considered will be different. You can contact one of the organisations below for more information:

- In Scotland - Care Information Scotland (08456 001 001, careinfoscotland.co.uk)

- In Wales - Age Cymru (08000 223 444, ageuk.org.uk/cymru)
- In Northern Ireland - Age NI (0808 808 7575, ageuk.org.uk/northern-ireland).

How much should the fees be?

The council should tell you how much they think it would cost (or what they would be prepared to pay) to provide you with the amount of personal, nursing or dementia care that you need in a care home. This is called your personal budget - or independent personal budget if you are going to be paying all the fees yourself. It is usually given as a weekly figure. This figure should be based on the level of care you need, and the local market rates to provide it.



Even if you intend to pay your own way, do get a care needs assessment and ask how much the council thinks your personal budget should be for the type and amount of care you need. You may need them to fund you when your savings are used up and if you've chosen a more expensive home than one the council can provide based on your needs, you may have to move! Knowing what the council thinks is a suitable amount can also be very useful if you need to negotiate home fees.

More reasons to get a care needs assessment:

- social services write down what your care needs are and give you a copy of this
- they can give you a list of local homes able to cater for your needs. Watch out. Some homes will charge more than what the council sees as a suitable amount to meet your needs
- the council has no excuse not to offer you the 12-week property disregard, if it applies to you.



Did you know.....

From April 2020 (if you live in England), you will need to have a needs assessment if you want any of what you spend on your care to count towards the care 'cap' of £72,000.

If you are already getting help from the council to pay your care fees when this new system comes in, they will set you up with a care account to track how much you are spending on your care. If the council is not helping you, you will need to contact them to have an assessment and set up a care account.

We explain the cap in more detail in our factsheet ' What does the Care Act mean for me? ' (to order a copy, call 0800 319 6611).

In the next chapter, we'll look at choosing a care home. Cost is a deciding factor because:

- even if your council will fund you, they have a limit to what they will pay, as long as your needs are being met
- your relatives (or a charity) may agree to top up what the council pays – but they'll have a limit, too. (We explain what top-ups are in Chapter 8 .)
- there's a limit to what most people can afford long term. A year in a nursing home costs between £25,000 and £55,000, or in residential care, between £19,000 and £40,000. You need to think long term. See chapter six about how to get financial advice.

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4 Choosing the right care home Choosing residential care is a big decision, and one made in a hurry if there's a health crisis such as a stroke. That's why it's so important to anticipate this eventuality and discuss your preferences with your family. Assuming you have now had a care needs assessment (see chapter 3) and have a copy of the written assessment stating the amount and type of care you need, this is what to do next. Social services should provide a list of local homes, some of which may charge more than others. Other sources of information about homes are:

- the Elderly Accommodation Counsel (EAC) - (0800 377 70 70, firststopcareadvice.org.uk)
- your local council's website
- the Care Quality Commission – see below
- findmegoodcare.co.uk



Did you know...about three-quarters of care homes are privately owned. Only one in 20 is run by a local council and one in five by a charity. NHS-run homes account for under one percent.

Councils don't run nursing homes. (source: carehome.co.uk)

Care homes must be registered and regularly inspected by the regulatory authorities below.

England: Care Quality Commission (03000 616161, cqc.org.uk)

Wales: The Care and Social Services Inspectorate for Wales (0300 7900 126, cssiw.org.uk)

Scotland: the Care Inspectorate (0345 600 9527, careinspectorate.com)

Northern Ireland: The Regulation and Quality Improvement Authority (028 9051 7500, rqia.org.uk)

Reading inspection reports is no substitute for a visit.



“Care Quality Commission (CQC) reports are, at best, ad hoc and a snapshot in time. They show standards of cleanliness and electrical safety but they don’t measure the things people value such as being made to feel loved, cared for and an individual.”

Bill, chairman of a care home company

Different homes cater for different needs Care homes offer personal care including help with washing, dressing, going to the toilet, eating and drinking. You can expect help to take medicines but staff don’t have to have nursing training. **Care homes with nursing care** offer personal care but also have to have a qualified nurse on duty at all times. They may have a higher ratio of staff to residents than a residential care home above. Suitable if you are too sick or frail to live alone but not ill enough to need hospital care. **Care homes with dementia care** are also called EMI (elderly mentally infirm) care homes. They often have a qualified nurse with dementia expertise. Everything from the building’s design to the leisure activities is geared to make people with dementia feel comfortable and secure. **Dual-care homes** accept a number of residents who need nursing or dementia care, and a number who need personal care only. A good choice if you need nursing but are mentally alert like Theo (story below), or if you might need more care later and don’t want to have to move twice. All should offer suitable outings and social activities - ranging from pleasant, safe gardens, to art classes or trips out.



Theo’s story

At 75, Theo had a stroke which left him unable to walk or swallow: he had to be fed in hospital through a tube in his stomach while his brain remained as active as ever. After six weeks, the hospital assessed him as ready for discharge and asked his family to look for a suitable nursing home.

Theo's wife wanted him to move to a pleasant residential care home near their house so she could visit daily. But the home wasn't registered to provide nursing. The social worker explained that a nursing home was Theo's only option given the skilled nursing he needed.

Theo's wife feared her bright husband would be bored and frustrated in a nursing home. She was advised to consider a dual-purpose care 'scheme' because it provided more activities for lively-minded residents and offered nursing home facilities on the same site. The nursing home had a place available and was convenient enough for regular visiting so Theo's family was confident he would be well looked after.



Did you know... you have a right to a place in a home which 'meets your needs', as specified in your care plan or written assessment, even if it is in a different country. You can choose a care home anywhere in England or Wales, or by arrangement in Scotland.



Did you know...If you and the council agree you need to go into a care home and they are helping to pay the fees, they must arrange it if you can't do it yourself and no-one else will act for you. From April 2020, you will be able to ask the council to arrange your care home placement even if you are paying all the fees yourself. You are more likely to choose a home you like if a relative or friend helps you.

Deciding your priorities You may have to compromise – a smaller room than you'd like, or further away from your family. But you should not be expected to share a room, unless you choose to. Other considerations are:

- do you want to stay local, move nearer family, or move to another area you know well?
- do you feel better amid the buzz of the town or the peace of the countryside?
- do you like a structured day or are you more easygoing?

- is it important to you to take your furniture or have your own bathroom?
- do you need a home which accepts pets?
- how important are good transport links?

A glossy brochure is no substitute for a visit Talk to residents, visitors and staff alike and don't be afraid to ask lots of questions. Check you get on with the manager as they set the tone for the home. It helps to know a person or friend who has moved in.



“If the receptionist gives you a smile and says hello, that’s a good sign. Beware of places where the staff look disgruntled or don’t have time to speak to you. Ask about staff turnover - if they keep leaving, why is this? The staff at a well-run care home

should welcome your questions rather than seeming defensive.” Alan, care

home CEO **Key questions to ask on a visit** Walking around and being shown the various rooms can tell you a lot. You could ask:

- are there facilities for residents to make themselves a cup of tea or a snack whenever they like?
- are there plenty of toilets within easy reach?
- if you have problems walking, could you see yourself getting around the home and managing in the bathroom?
- can residents have private telephones and do they?
- is there a garden or patio where you can sit outside? Are residents allowed to garden and is the garden easily accessible?
- is there a quiet lounge as well as a TV room? Are chairs grouped so that residents can chat?
- do the residents seem happy, alert, fully-dressed, busy, and engaged as far as possible with the staff and one another?



“What puts some relatives off – swirly carpet, seventies wallpaper – may make their elderly parent feel secure and comforted. They should remember who they are choosing for.” Mick, social worker It’s easy to forget an important question so make a list. **Ask:**

- about treating every resident with respect. Staff shouldn’t call you ‘Anne’ or ‘my love’ if you prefer ‘Mrs. Jones’.
- if visitors can come whenever they like. Can children and pets visit?
- what sort of social activities they arrange. Things you’d enjoy?
- about the food. Ask to see a menu. Is there a choice? Can they cater for special diets? Must you take all meals in a dining-room or can you have any meals in your own room?
- about the arrangements for seeing a doctor, dentist or podiatrist.



If you are terminally ill...check the home is linked to a ‘palliative’ or ‘end-of-life’ care team – nurses skilled at administering pain relief and giving emotional support. Some homes may not be able to provide the care you need and you may have to go into hospital or into a hospice. A good home will work closely with your GP but check first.



Planning to pay your own way? Even so, it’s very useful to know what the council would be willing to pay to meet your needs and to ask the home you’re visiting if they have any places contracted by the council. If your money ran out after a year, would the home be prepared to take you at the amount the council would pay? Explore the options eg, could you move to a less expensive room?

What to do if there are no vacancies Whoever is paying the fees, social services should be able to arrange for you to move into another care home, temporarily, while you wait for a vacancy in the one you prefer. **What to do if you are refused your**

choice of care home Your council should do everything it can to place you in your choice of care home and it should be prepared to enter into a contract with a provider it does not currently have an arrangement with. If your choice of care home cannot be met because the provider is not registered to meet your needs, the council should write to you giving you the reasons and it should offer you suitable alternatives. It should also inform you of the council's complaints process and if and when the decision can be reviewed. [Back to top](#)

Paying for care

Almost everyone has to contribute towards the cost of their care.

Does anyone get everything provided? Yes.

- people like Antoinette – see below - whose primary need is for medical care. She is entitled to fully-funded or continuing healthcare from the NHS. She needs the attention of skilled nurses and doctors rather than simply help with washing, dressing and eating.
- people who have had a compulsory stay in hospital for mental health treatment. Contact Mind (0300 123 3393, mind.org.uk) for details about Section 117 Aftercare.



Antoinette's story

The hospital told Antoinette, 69, that more chemotherapy for her cancer wouldn't help; the most they could do was keep her as comfortable and pain-free as possible. Her consultant said she might have only weeks to live and fast-tracked her for NHS continuing healthcare funding. The NHS would pay for care wherever she wanted it: in a nursing home, a hospice or her own home.

After exploring the options, Antoinette and her son, Lee, decided she'd feel more secure in a nursing home where there were carers and nurses 24 hours a day. The hospital social worker gave Lee a list of nursing homes to choose from, which could offer enough care and had the specialist equipment Antoinette needed. She moved from the hospital into the nursing home she had chosen. In the last four weeks of her life, she received loving care and regular visits from Lee and the grandchildren.

Do you qualify for NHS continuing healthcare?

Before discharging you from hospital, staff will screen you and if appropriate, refer you for a full NHS Continuing Healthcare assessment. If you are at home or living in a nursing home, you can ask your GP, care home manager or social worker to refer you.

What happens at the assessment

A registered nurse rates your needs in 12 different categories from nutrition to breathing, as low, moderate, high, severe or priority. If you score highly in four areas, you are entitled.

Turned down? You can ask the NHS to review its decision. For more information, read our factsheet: Continuing healthcare: should the NHS be paying for your care? or call one of our advisers on 0800 319 6789.

Need temporary care in a home?

A stay of up to 52 weeks is considered temporary. Whether you're staying for a few days after leaving hospital to help you recover, or receiving replacement care while your carer takes a break, you will most likely be charged for this. If your stay is temporary, the value of your home is not taken into account when the council works out what you can afford to pay. If you can't afford replacement care, you may be lucky enough to find a charity that will help with the cost. Try searching for grants through turn2us.org.uk , 0808 802 2000.

When it's free

After a hospital stay or fall, you might need short-term therapy or rehabilitation to get you independent again. If a care home is the best place to get this treatment, it will be free for up to six weeks.

How to work out what you'll pay towards care home fees

At your financial assessment, you'll be asked if you have capital and savings over £23,250*. The value of your home counts as capital unless any of the following needs to live there:

- your husband, wife, civil or unmarried partner
- a relative with a disability
- a close relative over 60

- a child under 16 whom you, or your former spouse - provided they're a lone parent
- have responsibility for.

There is more detailed information for homeowners in Chapter 7 .

Council help in England

Councils have upper and lower limits which they call bands. In England the upper limit for help is £23,250 and the lower limit £14,250. These capital limits will change to £118,000 and £17,000 in April 2020.

Capital and savings above £23,250? You'll have to pay your own fees for the time being.

Savings under £23,250?* You qualify for some council help.

Savings under £14,250? You get maximum council help but you'll contribute your pension and benefits less your Personal Expenses Allowance of £24.90 (in England - figures may vary in other parts of the UK).

Savings in between? You pay £1 a week for each £250 or part thereof of capital you have.

*Wales £24,000 and no lower limit; Scotland £26,250 and £16,250.

How your contribution is worked out – a typical example

The council assessed Gwen, 88, as needing a care home place costing £370 a week. She has savings of £20,000. She gets £135.15 pension a week plus Pension Savings Credit of £13.24 a week. Gwen's Attendance Allowance will stop because she qualifies for financial help from the council to pay her home fees.

Gwen's assessed contribution	
Pension and Pension Credit	£148.39
Gwen pays £1 for each £250 of savings she has between the council's upper and lower limits	£23.00
Total assumed income	£171.39

Less personal expenses allowance*	- £30.65
What Gwen has to pay (her 'assessed contribution')	£140.74
Balance paid by council	£229.26
Care home fees	£370.00

* When assessing how much you have to pay, the council must leave you an amount for personal expenses. Gwen lives in England so is allowed to keep a Personal Expenses Allowance of £24.90. She also claims Pension Savings Credit so may keep £5.75 of that benefit which is 'disregarded' by the council. The rest of her Pension Credit, however, counts towards what she has to pay.

Gwen's Personal Expenses Allowance: £24.90 + £5.75 = £30.65 a week

Less than £23,250* in capital and savings?

Get a care needs and financial assessment. If you need to move into a nursing home, get assessed for NHS funded nursing care.

Your council should help pay your costs but you'll contribute all income less £24.90 (in England) for personal expenses.

You must contribute £1 a week for every £250 in savings you have between £14,250 and £23,250.

Choose any local care home provided: it can meet your needs as per your needs assessment; is within your personal budget amount (what the council thinks should be paid for your care) and will agree to the council's contractual terms and conditions.

If you choose somewhere more expensive, a third party can 'top-up' the council funding but you can't top yourself up from your savings.

More than £23,250* in savings?

Get a care needs and financial assessment. If appropriate, get assessed for NHS funded nursing care.

Your council will pay the first 12 weeks of care costs if apart from the value of your home, your savings are under £23,250. They can support you longer through a deferred payments scheme.

You may be able to claim income support or Pension Credit if your property is up for sale. Phone the Pension Service (0800 99 1234).

Claim Attendance Allowance if you're not doing so already. (Not payable in Scotland if you're getting a personal care contribution towards fees).

Claim for NHS funded nursing care if applicable. This is paid directly to the home.

Make sure you can afford the home long term. Seek financial advice and review regularly.

*** Wales £24,000 and no lower limit; Scotland £26,250 and £16,250.**



Did you know...whether you are rich or poor, the NHS should pay for any nursing you require while in a home, provided you have been assessed as needing nursing.



"Auntie qualified for the council to pay her fees but then they told us the home she liked needed an extra 'top-up fee' to be paid by us. We weren't sure so phoned Independent Age for advice." (0800 319 6789).

Di and David, Tooting

You can download our factsheet [Care home fees: paying them in England](#) or call 0800 319 6789. See [chapter three](#) for contact details of organisations who can help if you live in other parts of the UK.

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Paying for care yourself

If you can afford to pay your own care fees, you are a self-funder. As you don't need the council to pay for you, it may seem pointless to involve them. The opposite is true. We recommend you have a care needs and if appropriate, nursing assessment before choosing a home. Take independent financial advice, too. The average amount spent on an older person's care in their lifetime is £60,000 so it's wise to proceed with caution.

Why you still need a free care needs assessment

- you get a copy of the findings known as the 'written assessment'. It helps prospective homes decide whether they're able to look after you
- you find out if the council (not you or your family) thinks you need residential care
- you find out how much the council would pay per week for someone who needs the type and amount of looking after that you do. You may need them to pay if you run out of money. Otherwise, you may have to move if you choose a home that's unsuitable or too expensive
- From April 2020 (in England), you will be able to set up a care account with the council to track your progress towards the care cap (see chapter three).

Why you still need a free nursing assessment

If you need skilled support from registered nurses as opposed to routine treatment - such as the dressing of leg ulcers - which is free under the NHS, you're entitled to NHS funded nursing care. This is currently £110.89, paid directly to the care home – this figure may change before April 2016.



Did you know... different residents in a home pay different rates just like hotel guests? Self-funders pay between £40 and £150 a

week more than council-funded residents. Councils pay less partly because they bulk-buy care home places.

Extra help to pay your fees

Over 65 and assessed as needing to live in residential care? Even if you have capital and savings over the council capital limit for help with funding, you can claim Attendance Allowance. It is unlikely you'd be going into a home unless you needed day and night care and supervision so you should qualify for the higher rate of Attendance Allowance.



John's story

After suffering a stroke, John needed to go into a nursing home. His bungalow was sold and raised £120,000 in capital. John also had a civil service pension giving him a total income of £420 a week. His social worker claimed Attendance Allowance for him at the higher rate, so he could claim £82.30 weekly and he was also awarded £110.89 a week of NHS funded nursing care to cover the nursing element of his fees. This brought John's income to £613.19 a week. The home cost £600 a week which was more expensive than homes available at his council's standard or usual rate.

This meant that John could cover most of the cost from his income. As he was paying his own way, he was also not limited to the personal expenses allowance of £24.90 a week (England).

Financial advice on how to pay your fees



Did you know... there are financial advisers who specialise in how to pay for long-term care. The Financial Services Authority (FSA) requires them to sit a special CF8 qualification so ask if they are CF8-qualified.

They'll ensure you claim any entitlements and help you decide if you can afford your chosen home over the medium and long term. Events which might affect your ability to pay are:

- a decline in your health so you need more care or more nursing
- home fees increasing – 5% a year is typical
- living longer than you expected.

There are several financial products on the market such as:

- an immediate need care fee payment plan. For a specific lump sum, you have the peace of mind of knowing your fees will be paid for the rest of your life.
- long term care insurance
- annuities.



The quality of financial products offered to pay care home fees varies considerably. Do your homework and be cautious before taking out such a product.



Violet's story

When Violet, 89, needed to move into a care home, her family approached a financial adviser. They used some of Violet's capital (from the sale of her house) to buy a long-term care home insurance product. They chose to defer claiming for a year to get a higher rate of interest. The rest of Violet's capital, her income and her Attendance Allowance covered the cost of the home she had chosen. After a year, the insurance plan started paying out. It guaranteed a weekly income high enough to cover fees, leave some extra for personal expenses and leave enough to cover any increases in care home fees for the foreseeable future.



Tommy's story

When Tommy, 69, needed to move into a nursing home, he chose a luxurious place close to his family in London. As he had a fairly large sum from savings and the sale of his house, he felt he could afford somewhere nice, if rather expensive. However, when he researched financial products, none of the products would pay out enough to cover the fees. As he loved the home, he decided not to buy a financial product but to pay his own way from his easy access savings account, his income, his Attendance Allowance and the Registered Nursing Care Contribution. He made a written agreement with the home: they agreed that if he paid his own way for five years, they would agree to accept the council's standard rate once his capital was reduced to the upper limit so he would never have to move.



"Say the care fee payment plan costs £80,000 and your home is worth £300,000, forking out for the plan is worth it if it gives you peace of mind to know you're going to be left with a legacy for your grandchildren."

Mick, social worker



"We looked at immediate need care fee payment plans because Grandad was 96 when he went into a home. We didn't take one out because they wanted about £80,000 and to be honest, we didn't think he would live long enough for it to be worth the investment. Four years on, he's had his 100th birthday so a plan would have covered the cost. Make your decision and don't regret it later because you've done the best you could at the time."

Karen, 61

Make sure your adviser shops around as financial products vary considerably.



Did you know... for an extra cost you can put in a 'capital protection' clause – or a money-back guarantee - that allows your family to get some of the lump sum payment back in the event of your early death. Standard plans do not provide for return of capital on death.

How to find specialist care home fees advice

You can find trusted, accredited financial advisers through the Society of Later Life Advisers (0845 303 2909, [societyoflaterlifeadvisers.co.uk/find-an-adviser](https://www.societyoflaterlifeadvisers.co.uk/find-an-adviser)).

Is the price you've been quoted reasonable?

Shop around and if necessary, appoint a third party to negotiate fees for you. Valuing Care (01273 757 233, [valuingcarefm.com](https://www.valuingcarefm.com)) collates care cost data and helps clients – councils as well as individuals – negotiate care home fees.

Valuing Care, the BBC 'Care calculator' (bbc.co.uk) and findmegoodcare.co.uk all offer online fees calculators to help you work out how much you are likely to pay in care home fees.



"Grown-up children don't like to haggle over care home fees in case they appear overly concerned with their inheritance. But paying just £50 a week over the odds will cost you £5,200 over two years."

Ray Hart, Valuing Care

Your written contract with the care home

Your contract should show:

- the care and services included in the fee and what is extra
- how much is payable and by whom (you, the council, the NHS, relative or a charity)
- how often the fee might go up and on what this increase is based
- fees payable if you go on holiday or into hospital
- your and the home's rights and duties; consequences for not keeping to them
- notice periods on both sides
- rules eg no smoking, no pets; permissions which might affect you (eg if another resident is allowed to have a pet)
- the complaints procedure.



Look carefully at clauses in your contract which allow the home to put up its fees in line with inflation or following a refurbishment.

Is your contract fair?

Only a solicitor can give you detailed legal advice on privately-funded contracts. The government website has a guide to Unfair terms in care home contracts ([gov.uk/government/publications/unfair-terms-in-care-home-contracts](https://www.gov.uk/government/publications/unfair-terms-in-care-home-contracts)) or call Independent Age (0800 319 6789).

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7 Advice for homeowners

Will you have to sell up to pay for care?

The rules are complicated and there are many grey areas. An Independent Age adviser will happily talk you through your options (0800 319 6789, advice@independentage.org). We cannot advise you on how to protect your assets or give legal advice on individual cases. For this, you need a solicitor or independent financial advisor.

As we said in Chapter 5, the value of your home counts towards your assets unless any of the following people live there permanently:

- your spouse or partner (from whom you are not separated or divorced)
- a relative over 60 or who is incapacitated. Incapacitated means entitled to Incapacity Benefit, Severe Disablement Allowance, Personal Independence Payment (formerly Disability Living Allowance) or Attendance Allowance.
- a child under 16 whom you are liable to look after.

These aren't the only exceptions – more details in our factsheet Care home fees: paying them in England (or call our advisers on 0800 319 6789). See chapter three for contact details for advice if you live in Wales, Scotland or Northern Ireland.



Did you know... at its discretion, a local council may ignore the value of your property if, say, your carer gave up his or her own home to look after you, lives there and has no other home.



Una and Roy's story

When Una went into a nursing home, her husband, Roy, decided to sell their family house and downsize to a bungalow. Una knew Roy wouldn't be able

to afford a bungalow with only his share of the capital and wanted him to have some of her share; the council agreed to this.

The house sold for £200,000 and the bungalow cost £150,000, leaving a surplus of £50,000. The council took the remaining £50,000 into account in Una's financial assessment.

You'll find more details about paying for care if you have a partner in our factsheet: Care home fees - paying them in England (or call us on 0800 319 6789).



Did you know... while councils have obligations in certain areas, they may use their discretion in others. Wherever they have an absolute duty to you, we have pointed this out.

Breathing space while you decide what to do

If apart from your home, you have under £23,250 in savings and don't have enough income to pay the fees, the council will contribute towards your care home bills for 12 weeks or until you sell your house, whichever is sooner. You don't owe the money back. This is called the 12-week property disregard and councils have to inform you of it. If you go into care temporarily, the disregard starts from the date the home takes you as a permanent resident.

If you have been paying all your own care fees, but later need financial help from the council because most of your savings have been used up, you will not get this 12-week property disregard. The council will expect you to start contributing towards the cost of fees from the sale of your property straight away. This is because you should have had time to sell your property whilst paying their own care home fees, and should have been able to foresee that your money was running low.



Don't assume whoever you speak to when you ring the council is the last word on the subject. Somebody might tell you: "We don't do the 12-week disregard" without understanding your enquiry. Be persistent. Ask to speak to someone more senior.

Option one – sell your home

You could sell your home and buy an Immediate Need Care Fee Payment Plan. This could mean you'll spend no more on care than the cost of the plan. It could provide an income for you while you need care and if you invest the balance of the proceeds, you might have an additional income or the potential of capital growth for an inheritance.



Did you know... the value of your property can be ignored for up to 26 weeks (or longer) for Pension Credit purposes as long you are taking steps to dispose of it. You can still receive Pension Credit during this period if you qualify.

Option two – get a loan from the council

A **deferred payments scheme** is a loan. The council agree to contribute towards your care home fees on the understanding that when your home is eventually sold, you will pay them back out of the proceeds. To ensure that you pay them back, there's a legal charge against your house.

In England, you have a legal right to a deferred payment agreement as long as your needs assessment shows that you would benefit from moving in to a care home, and

you have less than £23,250 in savings (aside from the value of your home). The council also needs to be confident that the loan would be secure and that they will be able to reclaim their money in the future.



Did you know... Councils in England can charge interest and an admin fee on this loan to cover the costs of lending the money to you for your care costs.



We get many calls from people who don't understand that a deferred payments scheme is a debt. They are shocked when the first official-looking letter arrives. It is a 'deferred payments statement' – and refers to an accumulated debt of, say, £30,000, for one year's care. It means £30,000 of the value of their relative's house is gone. When the house is sold, they will owe this amount to the council.

Gill, Independent Age advice worker



After the 12-week grace period, the council will go on paying Mum's fees. They are paid back when she dies and her house is sold.

Sheila, 63

When considering your loan, the council will value your home and also value your share in it.

Valuing your share of a property

You may be the legal owner of your home, but are you also the beneficial owner? Most people are both, but not always. The beneficial owner is the person entitled to gain from the sale and who:

- contributed to the mortgage
- contributed to the purchase price
- paid for repairs, alterations or a lease extension.

Any of the above can apply. It is your beneficial interest that matters to the council. Determining it can be complicated and we advise you to read our Factsheet: Valuing beneficial interest in property or speak to one of our advisers (0800 319 6789).

For more information about deferred payments, read our factsheet: Do I need to sell my property to pay for my care home fees?

Option three – rent out your home

If considering rental, do your homework! The property may increase in value but rent counts as taxable income. And any rental income from your home will be included in your contribution towards the fees.



At first we thought we'd let Dad's place to pay his care home fees. But when we considered what it'd cost to redecorate throughout, we weren't so sure. We all work full-time. It needed one of us to manage the redecoration and letting or we'd have to pay an agent. The lettings market isn't that lively around here. The Independent Age lady told us Dad continuing to own his home would mean he couldn't claim Pension Credit in the care home. In the end, we decided to take out a deferred payments scheme with the council while

we were selling the house. Once we've sold the house and repaid the council, Dad will be able to pay the fees in full.

Susan, 61

Giving away your home to avoid paying care home fees

Giving your home and other possessions away to avoid care home fees is called 'deprivation of assets'. At your financial assessment, you'll be asked if you ever owned a property. If you did, but don't anymore, they'll ask why.



Did you know...a council has to show a person got rid of their house with the intention of avoiding care home fees. They can look as far back into your affairs as they like.

Read more in our factsheet: What can I spend my capital on before moving into a care home? (or call an Independent Age adviser on 0800 319 6789).

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8 Top-ups and your council's duty towards you **What is a top-up?** Looking around, you'll find there's a wide variation in care home fees with many homes charging more than the council would be willing to pay. If you wish to move into a home that is more expensive than the amount offered by the council, the council or the home may suggest a top-up. This means your relative or in rare cases, a charity – see below, makes up the difference. This is called a third party payment or top-up. **Example of a top-up** Widower George, 91, lives alone in rented accommodation. He needs to go into a home offering personal care. His preferred home costs £600 a week. George is eligible for council funding but doesn't like the local homes available.

Weekly cost of home that George likes	£600
Less the council's payment	£480
Leaves a top-up for George's son of	£120

George will pay his assessed contribution from his income to the council and he will be left with his Personal Expenses Allowance of £24.90 a week.

Knowing your rights



"The council offered Dad two care homes which would accept the council's budget of £512 per week, but both were miles away. I found one nearby which charged £550 a week and where one of Dad's old friends was already living. With the help of Independent Age and Dad's social worker, I persuaded the council that this home met Dad's social need to be near friends and family. This had been noted in his care assessment. We pointed this out and the council agreed to pay the difference." Diana, 62



Did you know... the council is not allowed to ask for a top-up fee if you have chosen a more expensive home because there is no suitable care home place available at the amount the council is willing to pay.



Did you know... even if you are eligible for the council-funding, you may be told that the home you have chosen requires an additional top-up fee to be paid. If you are in any doubt, phone us on 0800 319 6789.

Who can pay top-up fees?

You cannot pay your own top-up fees unless:

- you are a homeowner who is getting a loan from your council secured against your home.
- you are a home-owner eligible for the 12-week property disregard period and your other savings are under £23,250. You can only pay the top-up yourself for that 12-week period.

The council must be satisfied that you are able and willing to pay this extra cost for as long as the council will be supporting you.

From April 2020, if you live in England and the council are helping to pay your fees, these restrictions are likely to be lifted. This means that more people may be able to pay their own top-ups in future.

The council will need to be confident that you can afford to pay a top-up on your fees as well as any contribution you already need to make towards the cost of your care. You will need to sign a written agreement with the council, so it's important to be sure that you can keep paying the top-up in the long-term

If you are not able to pay your own top-up (or if they want to), relatives, spouses, partners and friends can top you up.

Contracts and top-ups Contracts are normally one of the following:

- the council signs a contract with the home for the full amount of the fees and invoices you or your relative for the top-up
- the council signs a contract with the home agreeing to pay up to their agreed amount and the home invoices you or your relative directly for the top-up.

We recommend that the contract for a top-up fee should be agreed by THREE parties:

-
-
-

If you are in any doubt, speak to Independent Age on 0800 319 6789, or email advice@independentage.org. **The person topping you up should take**

independent financial advice before signing anything and consider:

- what would happen if circumstances changed and they could no longer afford to top you up
- that care homes usually increase fees annually but councils often don't increase the amount they are willing to pay in the same proportion so the top-up becomes disproportionately more
- what would happen if the fees increased to such a level that the top-up became unaffordable. Would the council take over your top-up or would you have to move?

Applying to a benevolent fund for help to pay a top-up

In very rare cases, charities agree to pay a small fee to top you up. Find out who might be able to help by visiting turn2us.org.uk, or calling their helpline on 0808 802 2000. You may qualify if you live in a particular area, and if you or your spouse worked in a particular profession. The services charity, SSAFA, will field requests from older people who served in any of the armed forces (0845 241 7141, ssafa.org.uk).

What to do if your top-up money is about to run out

Many callers in this situation ring Independent Age for advice. If you or your relative or friend can no longer afford to pay a top-up, talk to your council and the care home manager as soon as possible. If the top-up stops being paid and there is a shortfall in the fees, a debt could accumulate and you could be evicted. Independent Age (0800 319 6789) can advise.



Did you know... you may be able to claim back money already paid in top-up fees if the council's budget to meet your care needs is set too low.



Julie's story Julie's mother, Dorothy, had been in a home for six years, registered blind and suffering from dementia. Julie had been topping Dorothy's fees up, but the top-up increased each year and

she could no longer afford to pay. The council implied there was no other option but to move Dorothy to a cheaper home. Desperate, Julie called Independent Age. The adviser suggested she call social services to make sure they'd completed the 'risk assessment' section of the needs assessment to calculate the effect on Julie's mother of a move. "Spell out every possible reason why a move would be detrimental to your mother," the adviser said, "To support your case, make a list of why the new home will not be able to meet your mother's mental health and sensory loss needs as adequately as her present home." He continued, "Residents have a right to a copy of their written assessments to share them with their families and check their needs have been correctly represented. Details can get missed." So Julie emphasised that staff and other residents in her mother's current home understood her mum's preferences and knew how to keep her calm. Julie also argued that her mother's home specialised in working with people with sensory loss, which the cheaper home did not. Julie's case was successful and the council agreed to cover the full cost of her fees in her existing home. Julie even received some reimbursement of fees already paid.



Ron's story "I had been paying a substantial third-party top-up for a few years for my wife's care. I thought the council should have contributed more, and so did her GP and social worker, but the council disagreed.

Acting on advice from Independent Age and a solicitor, we contacted the council and told them we were going to seek a Judicial Review. They responded quickly, agreeing to increase the amount they paid and repay me more than £20,000 in top-up fees I had already paid, as well as my legal expenses. The best thing is that my wife is no longer worried about having to leave the care home where she is happy."

Top-ups are complicated. If you're about to sign a contract involving a top-up, phone Independent Age on 0800 319 6789 without delay.

You may want to read our factsheet: [Paying care home top-up fees in England for more information.](#)

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9 Settling in your new home

The biggest misconception about care homes is that once you move in, you give up any choice or control over your own life. Not true. You may do as you please provided you're safe and you respect others. This is your home, and if you struggled and felt lonely before, the quality of your life should improve with regular meals, stimulation, loving care, good equipment and company.

Seven tips to help you settle in smoothly

1. Tell carers how you prefer to be looked after

When you move in, you and the management will draw up a care plan. This sets out:

- your goals eg, "I want to continue my drawing classes"
- your preferences eg, "I like my bath in the evening. On Friday nights, I'd prefer a sandwich supper in my bedroom so I can listen to music on the radio."



"Good care is about good communication. Tiny details like whether Mr Thomas has a very sweet tooth can make him feel at home - or not."

Ian, former care home manager



Did you know...new guidance from the National Institute for Care and Health Excellence (NICE) says that care home residents must have as much choice as possible over their personal routines such as when they eat and sleep, and should be supported to take part in activities they enjoy. Your needs should come before what is most convenient for the home.



Did you know... if the council is paying for your care, it must carry out a review of your needs and how the home is meeting them, three months after you move in. After that, they should carry out a review at least once a year. You can request a review of your needs at any time.

2. Bring some personal items

It's comforting to see and touch your favourite armchair, dressing table or painting so bring them. If items are valuable, check the home's insurance policy and take out a separate policy if necessary.



"I knew it was a good home because they asked me to supply three photos of my client, George, at different stages of his life. The pictures provide a talking point. The people who help George to wash and dress are able to see within the frail old man, the person who has flown planes, grown championship marrows and even met the Queen."

Maggie, social worker

3. Install a personal phone

It'll give you a real sense of independence.

4. Find yourself a job!

If you have always kept busy, you won't be happy sitting about. So lay the table for dinner, arrange the flowers or tend the plants. Keep an eye on someone who's feeling low. You'll help the staff and make a valuable contribution.

5. Wear clothes that make you feel good

Velcro slippers and fleecy tracksuits are comfy but they may depress you if you've always worn a suit and tie, or fashionable clothes. Tell staff what you want to wear.

6. Make sure you feel safe and private

When you move in, the home will take an inventory of your possessions. You should have a lockable drawer or bedside locker, privacy curtains if you have chosen to share and a key to your bedroom door if you're safe to use it. Staff should knock before entering your room.

7. Think positive

Participate in the home's activities and think of the many advantages the home brings you, such as no more worries about falls in the night, housework or feeling lonely.

Attendance Allowance, DLA, PIP and other money matters

If you are paying the full fees yourself or have taken out a deferred payments scheme, you can continue to collect Attendance Allowance (AA) or Disability Living Allowance (DLA) or Personal Independence Payment (PIP). If you own your home, its value will usually take you above the capital limit for Pension Credit but if it is for sale, its value will be ignored for up to six months or longer.

If your Attendance Allowance, DLA or PIP stopped during the first 12 weeks of your stay during the 12-week property disregard, ask for it to be reinstated once you're paying the full cost of your care.

If your fees are being paid by the council, you can keep getting any mobility component of DLA or PIP that you are entitled to.

Going into hospital from a care home

If eligible, you will continue to receive Pension Guarantee Credit and other means-tested benefits for a hospital stay of up to 52 weeks. Attendance Allowance, PIP or DLA stops after four weeks which will affect any premiums you receive on your other benefits. Tell the Disability Benefit helpline (AA: 0345 605 6055, DLA: 0845 712

3456, PIP: 0345 850 3322) about your hospital visit or you'll have to repay any benefits accidentally overpaid.

Depending on your contract, the care home should keep your room for you while you're away but will expect to be paid. If you are likely to be in hospital for a while, you could ask the home to charge you a reduced rate.

Who pays for specialist equipment?

If social services assessed you as needing specialist equipment, it's the home's duty to supply it. The NHS continence service should pay for any pads and aids you have been assessed as needing. The NHS also pays for minor treatments such as the dressing of leg ulcers.



Did you know... you may have to pay extra for chiropody, hairdressing, outings and social activities. You may also have to pay extra if a staff member accompanies you to dental and outpatient hospital appointments.

Advice for relatives



"The ideal relative works with the home, not against it. Some relatives – particularly daughters – feel care home workers can never do enough for their parent, or do it right, and that's because they feel terribly guilty their relative is in a home at all."

Care home CEO



"The best kind of relative visits often and brings life to the home. The more difficult kind of relative is the one who doesn't understand what dementia is and doesn't accept that their parent has it."

Care home manager



"Build up a good relationship with the manager and nursing sisters. Get to know the nursing home doctor and be there during rounds, if you can."

Louise, whose parents were in a nursing home

How to make a complaint

If you're concerned about any aspect of care, you or your relative should raise it informally as soon as possible. Speak to the person or people directly involved and don't be afraid that staff will treat you less well if you complain. If your complaint isn't so easy to solve, put it in writing and keep a record. In our factsheet: Complaints about health and care services in England , there's advice about how to make a formal complaint (or speak to one of our advisers on 0800 319 6789).



"Misunderstandings sometimes escalate and staff can get defensive. They are only human and sometimes forget their instructions eg, to knock before entering bedrooms. A good care home manager will first

check the resident's physical illness hasn't caused the problem and look at every possible solution."

Jane, care home manager



Did you know... you should not be subjected to physical restraint in any way without your consent.

You may have heard about worried family members putting hidden cameras in their relative's room to get evidence of the care they are getting. The Care Quality Commission (CQC) have produced a leaflet, [*Thinking about using a hidden camera or other equipment to monitor someone's care?*](#) to help people understand what this may achieve, what you can do, and who you can turn to for help. Before making any decisions about using hidden equipment, we recommend that you read this information, or talk to someone at the CQC about your concerns (see below).

Abuse against older people is very rare. If you do have any concerns and have told the care home manager, you could also complain to:

- your council. Ask for the 'adult-safeguarding' team
- the police
- Action on Elder Abuse (0808 808 8141, elderabuse.org.uk)
- the Care Quality Commission (**03000 616161**, cqc.org.uk) - see chapter four for contact details of the relevant authorities for Wales, Scotland or Northern Ireland. They do not investigate individual complaints but they register them and investigate care homes they feel are failing to meet their standards.



"Mum gets very anxious at times. It made me angry that someone wasn't with her all the time as they claimed in the brochure to offer 24-hour care. The manager explained that 24-hour a day staffing doesn't mean each resident, personally, get 24 hours. On average, each resident gets 13-16 hours of staff time a week. She arranged for one of Mum's friends to sit with her at anxious moments and hold her hand - and this worked like a dream."

Catherine, 69

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10 Peace of mind

Just because you're in a home doesn't mean you can't be in control of your affairs. It will give you peace of mind if your paperwork is in order and your family, GP and the home know how you'd wish to be treated under all circumstances. We also give suggestions here for terminally ill care home residents.

Have you made a will?

If you die without one, your estate will be divided up according to a set legal formula, not necessarily how you would have wanted. We recommend you make a will if your circumstances are at all complicated, eg, if you and your spouse separated but never divorced.

You might like to specify cremation or burial, flowers or donations to a good cause, in a letter kept with your will. It's very comforting for relatives.

Mention any wish to donate an organ. Call the NHS Donor Line (0300 123 23 23 [organdonation.nhs.uk/how to become a donor](https://organdonation.nhs.uk/how-to-become-a-donor)).

How to hand over responsibility for your affairs

If you were to become severely incapacitated, would you want a trusted relative or friend to make decisions for you? **Lasting powers of attorney (LPA)** replaced Enduring power of attorney in 2007. There are two kinds: **a financial LPA** allows someone to manage property and financial matters for you; **a health and personal welfare LPA** lets another person decide on your care and treatment. This includes refusing medical treatment if you have specified this.

To be valid, LPAs have to be registered at the Office of the Public Guardian (0300 456 0300, gov.uk/power-of-attorney). They cost £110 each but you may qualify for a reduction. More details in our factsheet: Money and welfare: managing my affairs if I become ill , (or call us on 0800 319 6789).

Different conditions apply in Scotland and Northern Ireland.

Having your wishes respected under all circumstances

An **advance decision** to refuse treatment - also called a **living will** or in Scotland, an **advance directive** – is exactly what it sounds like. It is legally binding under the Mental Capacity Act, 2005 and doctors must respect it. **It is free and you don't need a solicitor.**

Have you heard the phrase **do not resuscitate** or **do not attempt resuscitation** ? It means that in certain circumstances, you wouldn't want nurses and doctors restarting your heart after an attack or collapse. You also might not want artificial feeding if you were enjoying no quality of life whatsoever. Families can find withholding treatment extremely difficult which is why you should discuss your plans with them.

Consider what you would want in the following situations. There are no wrong or right answers to these questions and your answers may change over time.

- You develop dementia and reach the stage where you no longer recognise your family. You're then diagnosed with pneumonia which would be fatal if it were not treated with antibiotics. Would you want antibiotics? Yes? No? Maybe?
- You have heart failure, poor health and difficulty walking very far. You're always tired and short of breath but alert and able to enjoy time with friends and family. One day, you have a heart attack and your heart stops beating. Would you wish to be resuscitated. Yes? No? Maybe?

Discuss your Advance Decision with your doctor and family and ask both to keep a copy of it. Update it if your health or wishes change. You can download a free form from Compassion in Dying, (0800 999 2434, compassionindying.org.uk).



Did you know... LPAs and advance decisions are both ways you can refuse treatment in advance. An LPA would override an Advance Decision so keep your relatives informed and ask them to respect your wishes.

Appointing or becoming a deputy



"Auntie Pat had severe dementia. She hadn't arranged Power of Attorney. Yet someone had to pay her bills and sell her house after she went into a home. Auntie ran her finances carefully and wouldn't have wanted our inheritance eaten up by solicitor's fees to do it. So I applied to be her Deputy. It was a lot of work but I'm glad I did it."

Christine, 67

More details in our factsheet: Money and welfare: managing my affairs if I become ill (or speak to one of our advisers on 0800 319 6789).

Avoiding family disagreements

If you have more than one child or sibling, make sure they know your wishes. This can avoid distressing disagreements at your bedside.



"Dad was 86, had had dementia for five years and was doubly incontinent. Then he caught a bug. He was very poorly and close to the end. At one point, he whispered to me, "Let me go". But my sister is a GP and I think the nursing home was terrified of being sued. They fed him through a tube in his nose and five minutes later, he was sick, then died. I wish he had made an Advance Decision. It wasn't a dignified end and my sister and I quarrelled bitterly. We were just so upset. We've made up since though and are fine."

Bridget, 50

Advice for people who are terminally ill

Something on your mind? Tell a trusted member of staff if:

- there's an item you wouldn't want relatives to find because it might upset them
- you'd like a priest or religious elder to say a last mass or prayer
- you're worried about who's going to look after the family
- you want to make your peace with a particular person
- you're worried about funeral arrangements
- you're afraid of pain.

If you are not sure what to expect in the final stages...

Marie Curie Cancer Care has a leaflet **End of Life – the facts** . It will help you, your relatives and friends to understand what is happening (0800 716 146, mariecurie.org.uk).



Did you know... under UK law it's illegal for doctors to give you more painkillers than you need with the intention of ending your life more quickly.

Pleasure is important even at end of life

You are entitled to dignity, control, freedom from pain and pleasure at the end of life. Small treats – say, thickly buttered scones if you've been on a low-fat diet - are important. What about some of your favourite DVDs or a short outing to a place with meaning to lift your spirits.



"Being ill means so much is done for you and to you. It's important to feel you have some control even if it's just having your bed placed by the window."

Freddie, care home resident with terminal cancer



"Without fluids, people die more quickly. It isn't pleasant for them and they can hallucinate if thirsty which can be upsetting for their relatives. We gave one chap strawberry ice lollies because they were refreshing, sweet and soothing. He liked cold drinks with ice, too."

Sarah, member of a palliative care team



"My father-in-law was dying very slowly of cancer. He'd been a Japanese Prisoner of War and he'd said he didn't want any fuss when he went because he'd seen so many comrades die in unmarked graves. He seemed troubled. I found a Japanese woman in our area who arranges Anglo-Japanese reconciliations. She came to his bedside, gave him a big hug and asked him to forgive his captors. I asked my father-in-law if it had helped and he said, "Yes, tremendously." Then he died, very peacefully."

Gillian, 55

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