My Future Care

Handbook

PLAN for TOMORROW, LIVE for TODAY

This Handbook belongs to:

Name _____

Address _____

_____

_____

Phone number _____

Email address _____

NHS Number _____

Hospital Number _____

This Handbook has been produced by Mycarematters 2020 CIC, a not-for-profit social enterprise dedicated to improving people's experience of care in care homes, hospitals, hospices and in their own homes.
Email info@mycarematters.org Phone 01403 210485.

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Enquiries

For further copies of the Handbook please email info@mycarematters.org or phone 01403 210485.

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west sussex county council

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healthwatch West Sussex
Confused by local health and social care services? We're here to guide you.
0300 012 0122
helpdesk@healthwatchwestsussex.co.uk
www.healthwatchwestsussex.co.uk

RSA

What is the **My Future Care** *Handbook*?

It is very easy to put off thinking about our future, even when we know there are certain decisions we should probably be taking, conversations we should be having. It's not made any easier if we're not sure where to start or which decisions and documents are the important ones.

None of us knows what's around the corner. If we keep putting off these decisions we might find ourselves in a position where it's suddenly too late and we are unable to communicate our wishes. That can make things difficult for family members and healthcare professionals who may have to guess what it is we would want to have happen. And, of course, family members may have different points of view which can make things awkward.

The **My Future Care** *Handbook* has been developed to pull all those decisions and tasks together into one place, explaining what each decision / document is for, how it will be used and providing guidance on how to complete it.

The intention behind the **My Future Care** *Handbook* is to encourage you to think about these things earlier, and give you and your family and friends a sense of control and peace of mind. We want to enable you to make decisions from an informed position, and then to get on with living your life!

What it is not...

The information provided here is not a substitute for advice from healthcare professionals or lawyers. If you are at all unsure about any aspects of a particular task, decision or document, do ask for help. You will find guidance in each section regarding the kind of help you may wish to request, bearing in mind that we are all different and some people will feel comfortable taking on more themselves than others.

Who is the **My Future Care** *Handbook* for?

Tick all that apply...

- [ ] Are you 18 or over?
- [ ] Do you live in England? (If not, the contents may still be relevant, but do not assume the information contained here is valid for your country. We expect that future copies of the Handbook will be valid for the whole of the UK.)
- [ ] Are you reaching an age or state of health where it's starting to feel a little uncomfortable thinking about the future?
- [ ] Would you like to make your family aware of your preferences for your future care?
- [ ] Are you concerned there might be a time in your life when you may not be able to communicate your needs, either temporarily or as a result of a long-term condition?
- [ ] Do you have a diagnosis of a life limiting illness?
- [ ] Have you lost the capacity to make decisions for yourself? (A family member, carer or healthcare professional is reading and completing this on your behalf.)

If you have ticked any of the above statements, this Handbook is for you!

You'll have realised that all adults will tick at least one box; that's because there are a few tasks we should all complete. Once you have them in place you can relax in the knowledge that they're there when you need them. You can then forget about them until they're needed or you experience a life changing event that may mean you wish to update your decisions.

How to use the **My Future Care** *Handbook*

"This Handbook is literally a one-stop-shop for anything and everything future care related. It takes what is a really tough topic and makes it as easy to address as it's ever going to be."

Beth Britton, expert campaigner and consultant in ageing, health and social care.

There's no need to tackle all this in one go!

Have a browse, perhaps decide which one or two tasks are most relevant to your current circumstances. Get a sense of the decisions you might like to think about at some point.

Remember, this is your Handbook. It is entirely optional as to whether you do any or none of these tasks. However, hopefully you will recognise the value of some if not all of them in making life easier for your family and/or those health and social care professionals supporting you, as well as ensuring that your own needs and wishes are met.

You may wish to talk it through and/or complete some or all of the various tasks with a family member or a health or social care professional.

For some of the documents or just for some general advice you may wish to consult a lawyer. Equally, if your situation is straightforward and you are comfortable doing so, it may be appropriate to create your documents without external support. We provide templates to help, as well as links to relevant websites when appropriate. At the back of the Handbook you'll find some Factsheets on a wide range of topics.

If you ticked two boxes on page 6 you may wish to focus first on the orange section (pages 17-24). These are tasks we should all do, in preparation for a time when we might not have the capacity to make decisions for ourselves. You never know what's round the corner. Also take a look at the purple items (pages 12-14).

Ticked more than two boxes? In addition to the orange and purple sections you may wish to consider the green tasks (pages 15-16 and 25-42).

Completing this on behalf of someone who no longer has capacity? (If you are not sure how to measure capacity, you will find further

continues...

How to use the **My Future Care** *Handbook* *contd.*

information in the Factsheet on page 56.) Note that whilst some forms can be completed on a person's behalf, not all can and even then it depends on your role.

Whilst some of these tasks are more important than others, there is no right or wrong order in which to tackle them.

Ensure that this Handbook is visible to all health and social care professionals supporting you. Ask them to add their contact details on page 10 and to add the date each time they visit.

(If you have carers visiting you on a daily basis they will have their own paperwork and do not need to add their visits here.)

You will see QR codes (square barcodes) dotted through the Handbook. If you use a smart phone or tablet, you can use a QR reader App to use these and be taken straight to a website.

If you are reading this document as a PDF and you'd like the page content read out loud, use the **'Read out Loud'** feature in your Adobe PDF reader: go to View and activate Read Out Loud, then click on the paragraph you'd like to hear.

Contents

Colour Coding

Purple: A good place to start

Green: Make life easier for your family and the professionals supporting you, plus gain a sense of control over your future

Orange: If you do nothing else, do these...

Red: Useful factsheets on a variety of topics

Names and contact details

My primary contact is (name of family member / friend / supporter / carer / advocate):

_____

They are happy to be ☐ emailed and/or ☐ telephoned by any of the people listed below.

Their email address is:

_____

Their telephone number is:

_____

Add below the name and contact details of any health and social care workers or other people supporting you. This may include your GP, social worker, nurse and others. This not only helps you keep track of who is supporting you, but also helps them understand who else is involved in your care.

Name: _____

Organisation: _____

Tel No: _____

Email: _____

Visited (dates): _____

_____

Name: _____

Organisation: _____

Tel No: _____

Email: _____

Visited (dates): _____

_____

Names and contact details *contd.*

Name: _____

Organisation: _____

Tel No: _____

Email: _____

Visited (dates): _____

_____

Name: _____

Organisation: _____

Tel No: _____

Email: _____

Visited (dates): _____

_____

Name: _____

Organisation: _____

Tel No: _____

Email: _____

Visited (dates): _____

_____

Name: _____

Organisation: _____

Tel No: _____

Email: _____

Visited (dates): _____

_____

A further page is provided at the end of the Handbook if required

What are your priorities?

This Handbook gives you the opportunity to complete a range of activities relating to your future, and information on each of them.

You may not be clear about your priorities until you have browsed the contents. Don't worry, it's here for you to come back to when you have a better idea of what feels most urgent. And remember, everyone's circumstances are different, so what's vital for one person is less relevant for the next.

	Tick when read	Do this now	Do this later	No need for this	Done
First thoughts about future care					
Bucket List					
Practical tasks					
Creating a Play List					
Writing your Will					
Letter of Wishes					
Mycarematters profile					
Lasting Power of Attorney					
Advance Statement					
Advance Decision					
Do Not Attempt CPR					
Organ / Tissue Donation					
Funeral Preferences					
Financial Planning					

First thoughts about future care

"If I have a terminal illness and I am close to death I don't want my life prolonged."

"I want to know that Charlie, my spaniel, will be cared for."

"I'll let my family decide whether I should move to a care home."

"I'd like my son James to speak on my behalf if I'm unable to communicate."

"It's really important to me that I do everything on my bucket list."

"I'd like to stay in my own home for as long as possible."

Whether fit and healthy or living with a medical condition that may shorten our life, we all reach a time when it is appropriate to start thinking about the things that will be important to us as we progress towards the later stages of our life.

This is an opportunity, perhaps before you look at anything else in this document, to jot down any initial thoughts you may have regarding your future care and end-of-life care.

This is purely for you to record your thinking now, and you can select below whether you'd like healthcare professionals to take note of these comments. There is ample scope later in this document to expand and formalise your decisions and preferences.

The sample statements on the left may help you to think about what's important to you...

☐ I would like healthcare professionals to take note of my comments.

Completed (date) _____

There is space for further notes at the back of the Handbook.

Bucket List

"Creating a bucket list helped me think about what is really important to me for the years I've got left."

Charlie, Essex

What is a bucket list?
A list of things you still want to do in your life.

Where can I go for help to complete this if necessary?
You may wish to create your bucket list with family or friends.

What should I do with it?
Give yourself some realistic target dates and enjoy the satisfaction of ticking them off when completed!

Are there things you've been meaning to do but haven't got around to? It might be as simple as getting in touch with an old friend you've lost contact with, or as ambitious as climbing Everest. But if you want to tick everything off, you may want to keep them vaguely realistic!

Write them here, and share with others, or not, as you wish. Then perhaps set yourself some targets for when you might get them done by.

Things I still want to do	Target date	Completed date
1.		
2.		
3.		
4.		
5.		
6.		
7.		
8.		
9.		
10.		

Practical tasks

The idea of the suggestions below is to provide you with peace of mind, help you to maintain your independence and avert a crisis if, for example, you have an unexpected stay in hospital.

	I do / don't want to do this: ✓×	Arrangements made
Leave a key to your home with someone you trust, preferably someone who lives close by and who is happy to be contacted by people involved in your care, now or in the future.		
Leave details of where to find appropriate passwords with someone you trust, or in a place where they will be found by that person when necessary.		
Make arrangements for your pet(s) to be cared for in case you are away from home overnight, or longer.		
Consider arranging a free Safe and Well visit from your local fire service who will offer advice on how to make your house safer and, where appropriate, fit smoke alarms or other specialist fire detection equipment free of charge.		
Write out and give to an appropriate person specific information about your home that may be useful if you're not there to explain, for example: - Where the stop cock is - Insurance information - Garden routine e.g. any special plants that need particular care - How to turn heating/fire on - Any quirks of the house		
Tidy up any financial loose ends that may otherwise cause problems for your family if you are not in a position to see to them yourself.		
Find out if you are entitled to Attendance Allowance: You will qualify if you have reached State Pension age and need care or supervision because you have an illness or disability. Look online or call the Attendance Allowance helpline 0800 731 0122.		
You may like to research personal alarms, fall detectors, medication dispensers and other technology designed to help you cope in later life.		

Create a Play List

"We just managed to do this in time for Dad to be able to tell us what he'd like on his play list.

Now he struggles to communicate but we can see the pleasure on his face when he listens to his favourite tracks."

Jane, Daughter

What is a Play List?
A Play List is a list of the tunes that are most deeply attached to your memories and emotions or, more simply, music you like to listen to!

Who can help me with this if necessary?
Enjoy completing this with friends and/or family members.

What should I do with it?
Either just keep it as a record of the music you like which might be useful for people caring for you now or in the future, or create a Play List online, at https://www.playlistforlife.org.uk/

A few prompts to get you started:
Are there any songs or artists linked to your childhood?
Do you like the kind of music played at nightclubs/discos?
Do you or did you go to concerts?
Are there TV theme tunes that hold memories for you?
Do you have any favourite Christmas songs?
Any wedding songs, perhaps music played at the first dance?
Are or were there any songs sung at family parties?
Are there any songs from holidays: music sung in the car or summer hits?

Writing your Will

"Seeking advice from qualified experts will ensure your wishes are met, having given consideration to your personal circumstances to protect those who need protecting, avoiding possible claims against your estate and mitigating Inheritance Tax."

Irwin Mitchell Solicitors

What is a Will?
A Will is a legal document which sets out what you want to happen to your assets after your death and who you appoint to carry out the terms of the Will.

Who can help me with this if necessary?
In most cases, it is recommended you take legal advice to ensure your Will is legally valid and achieves your objectives. STEP OR SFE accredited Solicitors are specialists in this area.

What should I do with it?
Store your Will in a secure place (see below) and tell your Executors where it is.

Preparing a Will is not as difficult or expensive as you might think, but it is important to take advice in most circumstances. You may be able to get a simple Will written for free, either during months designated 'Free Wills Months', or by choosing to leave a gift to charity: many national charities are part of the National Free Wills network and will pay for the cost of drawing up a simple Will.

There are 'do it yourself' Will templates available online or in paper form from certain newsagents if you wish to do it yourself.

If you have been diagnosed with a progressive illness such as dementia, it is important you do not delay this until a time when the question might arise as to whether you have the requisite mental capacity for making a Will. Having to prove you have capacity can be time-consuming and upsetting.

Executors
These are the people who will carry out the instructions you leave in your Will: you can choose up to four. Choose people you trust and who are good with paperwork. You can also appoint a professional executor, but remember that their costs will be paid by your estate. A professional Executor is advisable where there may be conflicts in the family, complicated or foreign assets to deal with or Inheritance Tax to pay.

Funeral instructions
You can use your Will to say something about what you'd like for your funeral. However, because it is not as easy to change your Will as it is to update a separate document, consider setting out

continues...

Writing your Will *contd.*

your wishes for your funeral on the form provided on page 41 and refer to it in your Will and/or your Letter of Wishes.

Inheritance Tax
In some cases, having a Will can help to reduce the amount of inheritance tax that needs to be paid from your estate. You may wish to check with a financial adviser and/or solicitor how the current law affects you.

Legacies for your favourite charity / charities
If there are one or more charities you like to support, you can choose to leave them a donation in your Will.

Storing your Will
There are various ways to do this. Your solicitor may store it for you at their offices. If you store it yourself be careful not to attach any other documents to it, such as with staples, paper clips or sellotape. Do not amend it. See the Factsheet on page 57 for further information.

Will Planner
Use the planner on the following page to set out the information a solicitor will need to know.

Further reading and resources:
https://www.gov.uk/make-will/writing-your-will

Solicitors for the Elderly can put you in touch with a local lawyer: https://sfe.legal/ or phone 0844 567 6173.

Action List

- [ ] It is usually advisable to take legal advice
- [ ] Complete the planner, or use one provided by your solicitor
- [ ] Make an appointment with a solicitor, or create your Will online or on a do-it-yourself paper version
- [ ] Tell your executors where your Will is being held / stored
- [ ] Review your Will every 2 – 5 years to ensure it continues to reflect your wishes. (You will only be able to create / change your Will if you are deemed to have the requisite mental capacity to make a Will.)

Will Planner

Use this planner to set out the information a solicitor will need to know.

Your Details

Full name:

Address:

Telephone number(s):

Your Spouse or Partner

Full name

Address (if different to yours):

Telephone number(s):

Your Children

Full name:

Address:

Date of birth:

Full name:

Address:

Date of birth:

Full name:

Address:

Date of birth:

The Value of your Estate

What you own

Home, other property / land	£
Car	£
Home Contents	£
Money in bank / building society accounts	£
Other savings	£
Total:	£

Any debts

Mortgage	£
Loans and overdrafts	£
Credit cards	£
Total:	£

Will Planner *contd.*

Your Executors

Who would you like to carry out the instructions set out in your Will?
You can appoint up to four; it is usual to appoint two.

Full name:

Address:

Full name:

Address:

Your Bequests

Specific items such as a family heirloom or piece of jewellery

Full name:

Item:

Full name:

Item:

Specific amounts of money

Full name:

Amount £

Full name:

Amount £

Who would you like the remainder of your estate to go to, after your debts have been paid off and your other instructions carried out?

Full name:

Percentage %

Full name:

Percentage %

Letter of Wishes

"Writing a letter of wishes made me sort out lots of loose ends that would have been unfair to leave my family to deal with."

James, Milton Keynes

What is a Letter of Wishes?
A Letter of Wishes is a document that accompanies your Will. It is not legally binding but can provide supplementary information to your executors regarding your wishes. You must take care that a Letter of Wishes does not contain anything that could conflict with your Will.

Who can help me with this if necessary?
It is possible to write a Letter of Wishes yourself but, if at all uncertain, speak to a solicitor.

What should I do with it?
Your Letter of Wishes should be signed by you, kept with your Will in a secure place and make reference to the Will to which it relates.

Other name for Letter of Wishes
Memorandum of Wishes

The value of writing a Letter of Wishes is that you can be non-specific in your Will as to who might receive certain items and then provide the details in the Letter. In this way, if you change your mind you can amend your Letter without having to re-write your Will.

After probate has been granted, whilst your Will becomes a public document, the Letter of Wishes does not, unless it is required as evidence by a Court. You may need to advise your executors of certain reasons for the provisions in your Will, which you do not want the beneficiaries or others necessarily to see.

It is an opportunity to make clear that someone who might have thought they would have been mentioned in your Will has been intentionally excluded, to avoid challenges to your Will after you have died.

It is important to understand that a Letter of Wishes is not legally binding so the executors are not legally obligated to follow any requests made in the letter.

Letter of Wishes *contd.*

Start your letter with the following statement:
'I make this letter in reference to my last Will and Testament dated the (insert date) and wish, without imposing any legal obligation on you my Executors and Trustees, that you act on it accordingly.'

The Letter of Wishes might be a convenient place, if you have not done so elsewhere, to refer to some or all of the following:

- Funeral wishes (see page 40)
- Details of your funeral plan if you have one (see page 44)
- List of people to be informed of your death
- Whereabouts of various documents (birth and marriage certificates, National Insurance number, pension document, benefit book, annulment of marriage etc)
- Bank accounts
- Building society accounts
- Saving accounts
- Shares
- Life assurance / insurance policies (car/life/content/house)
- Motor vehicle documents
- Hire / credit / rental agreements
- Property title deeds
- Income tax details
- Pensions
- Credit / debit cards
- Mortgage details
- Information to help your Executors identify specific items you are gifting e.g. gifts of a sentimental value with photos or descriptions of the items, you may also wish to leave a personal message for the recipient.
- What you would like to happen to your digital 'assets': social media accounts etc. See https://digitallegacyassociation.org/

Lasting Power of Attorney (LPA)

What is a Lasting Power of Attorney (LPA)?
A Lasting Power of Attorney enables you to appoint one or more people (known as 'attorneys') to make decisions on your behalf if you have lost the capacity to do so for yourself.

When should I create an LPA?
None of us knows what is round the corner, regardless of our age or state of health. However, the older or more frail you are the more important it is that you create an LPA without delay.

Is an LPA a legal document?
A Lasting Power of Attorney is a legal document and the attorneys you appoint have legal rights and responsibilities.

Why can't my next of kin take decisions on my behalf?
Next of kin has no legal meaning and cannot consent to, for example, providing or withholding care. You can appoint, with their agreement, the person you think of as your next of kin to be your attorney.

What if I have lost capacity before I make an LPA?
Attorneys must be appointed whilst you have capacity. If you have not done so, a deputy can be appointed by the Court of Protection to make decisions on your behalf. It is a slow and expensive process and a deputy's powers are restricted.

Do my attorneys have control over my affairs whilst I still have capacity?
There are two kinds of LPA and the answer to this is different for each. See below for further information.

Who can help me with this if necessary?
You can create an LPA yourself, but you may wish to take legal advice, particularly if your situation is not straightforward.

What should I do with it?
Once you have an LPA you need to register it with the Office of the Public Guardian (you can do this at the same time if using the online service) and give certified copies to your attorney(s).

continues...

Lasting Power of Attorney *contd.*

There are two types of LPA:

A Property and Financial Affairs LPA gives your attorney authority to deal with specified property and finances. If you want to make an LPA which only deals with certain matters, you should make sure that it is drawn up in such a way as to ensure the attorney is very clear about what authority they have to deal with your affairs. The Property and Financial Affairs LPA comes into effect as soon as it is registered, with your authority, unless you include instructions otherwise.

A Health and Welfare LPA allows the attorney to make health and welfare decisions on your behalf. It should be registered immediately but it only comes into effect when you lack mental capacity. This may mean it is in effect one day and not the next. Needing more time to understand or communicate does not mean you lack mental capacity. See Factsheet on understanding mental capacity on page 56.

It is important to remember that anything done under the authority of the LPA must be in the person's best interests. The same person or person(s) can act as attorney(s) for both LPAs.

You must be 18 or over and have mental capacity (the ability to make your own decisions) when you make your LPA.

Further reading/ resources:

https://www.gov.uk/power-of-attorney

Solicitors for the Elderly (SFE) can put you in touch with a local lawyer: https://sfe.legal/ or phone 0844 567 6173.

Action List

- [ ] Take legal advice if you are at all unsure
- [ ] Choose your attorney(s), ensuring they are appropriate and happy to take on the role, and understand their responsiblities
- [ ] Choose your certificate provider (a professional able to confirm you have mental capacity)
- [ ] Complete the form online or request a paper form by calling the Office of the Public Guardian on 0300 456 0300.
- [ ] Store the original in a safe place and give your executors copies that have been signed and certified by you as an exact copy. (A lawyer will need to do this if copies need to be made after you have lost capacity.)

Create a Mycarematters profile

"It's a great way to remind staff that this person is a unique individual with their own tastes and preferences."

Gill, Daughter

What is a Mycarematters profile?
A Mycarematters profile is a way of sharing your needs and preferences with healthcare professionals, in the event you can't communicate those things for yourself.

Where can I go for help to complete this if necessary?
You might enjoy completing this with one or more members of your family, or one of the people supporting you might find it helpful to complete it with you so as to get to know you better.

What should I do with it?
There are a variety of ways your Mycarematters profile can be used to help people care for you – see below.

Any of us might find ourselves receiving care at home, in a care home or in hospital and be unable to communicate our needs and preferences, temporarily or otherwise. By providing that information in a quick and easy format you will help busy staff care for you in a more person-centred way.

Don't wait for when you might need it, do it now so it's ready, just in case. Keep a copy with other paperwork or in the bag you would expect to take to hospital.

If you have carers coming in to your home they will find this a useful at-a-glance guide of your needs and preferences – keep it where it can easily be seen.

If completing by hand we have provided two forms: one is overleaf and can be torn out, the other is in the pocket at the front of the Handbook (on bright yellow paper) and is designed to go on the wall behind the bed. Either or both can be used at home, in a care home or in hospital.

If using the free online version you have the advantage of being able to update it at any time, and there is space to store other information as well. Print out a copy for care / hospital staff and, if you wish, provide them with your unique Mycarematters code to access your online record. Link to Mycarematters via the QR code on the left or via this link: www.mycarematters.org.

My Name is Elizabeth Patient, I like to be called Betty

Date created: 12th December 2018 10:48 am / Date Updated: 12th December 2018 11:56 am

Display profile: Yes - Betty requests that this profile be displayed behind the bed or as deemed appropriate.

What aids I need for my mobility.
I use a zimmer frame.

My favourite meal(s) and food I dislike or can't eat.
I hate overcooked vegetables. I don't eat red meat these days, because it's so bad for the environment.

What my hearing is like (better on one side, hearing aids?)
My hearing is better on my right side, though I don't wear hearing aids.

How I take my tea or coffee and drinks I like or dislike.
I like strong black coffee, no sugar. I hate ordinary tea, but quite like things like lemon and ginger, or mint tea. If I'm thirsty I prefer water to orange squash.

What you need to know about my eyesight and glasses.
I am very shortsighted, but I now also need to wear reading glasses, so I have two pairs.

My allergies, phobias and fears.
I am scared of birds.

How I demonstrate that I am in pain.
I curl up in a ball and don't like anyone touching me.

The level of assistance I need for my personal care.
I am scared of birds.

What bedding / pillows I like and my preferred routine.
I get neck ache if I have more than one pillow. I tend to go to bed about midnight, and I'm usually awake by 6 am.

My likes / dislikes and my preferred bathing routine.
I prefer showers and tend to shower in the morning.

What I'd like you to know about my teeth or dentures.
I have my own teeth and I can brush them myself, but might need prompting.

My preferred clothes / footwear.
My family bought me some very comfortable and supportive slippers that are good for preventing me falling. I have a comfy cardigan that I particularly like.

My favourite music.
I love the music from musicals. I used to enjoy listening to the Lian King music with my eldest grandson Luke.

The activities that I am interested in.
I used to knit until my arthritis got too bad. As a child I was a keen swimmer and swam for my school.

Television and radio programmes I like.
I don't like much on TV these days. I used to enjoy Crossroads. I listen to Radio 3 sometimes.

My previous or current occupation(s).
I used to work part time in the local corner shop. I also worked as a volunteer in my local hospital.

Dates that are important to me, and why.
1st January is my wedding anniversary. My husband died 20 years ago.

The most important people in my life.
My children Simon and Sarah and my 9 grandchildren. Some of them live in Australia.

My pets, favourite animals, and animals I don't like..
I don't particularly like cats, and I'm scared of birds.

My spiritual beliefs and practices.
I go to church at Christmas and think of myself as a Christian.

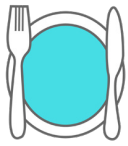
MY MYCAREMATTERS PROFILE

My name is:

I like to be called:

Patients / families: to create an online version of this profile go to www.mycarematters.org. Date created / updated:

What aids I need for my mobility.



My favourite meal(s) and food I dislike or can't eat.

What my hearing is like (better on one side, hearing aids?)

How I take my tea or coffee and drinks I like or dislike.

What you need to know about my eyesight and glasses.

My allergies, phobias and fears.

How I demonstrate that I am in pain.

The level of assistance I need for my personal care.

What bedding / pillows I like and my preferred routine.

My likes / dislikes and my preferred bathing routine.

What I'd like you to know about my teeth or dentures.

My preferred clothes / footwear.

My favourite music.

The activities that I am interested in.

Television and radio programmes I like.

My previous or current occupation(s).

Dates that are important to me, and why.

The most important people in my life.

My pets and favourite animals, and animals I don't like.

My spiritual beliefs and practices.

Space for additional Information, such as whether you are left or right handed, what do you normally keep on your bedside table, perhaps what makes you smile or anything else you'd like caring staff to know...

Advance Statement of Preferences

"I wished we had conversations about mum's care preferences before her vascular dementia diagnosis. After mum's diagnosis, discussions about the future were fraught. Towards the end we didn't know what quality of life she considered adequate, to justify medical interventions. In the end, I'm happy with the decisions we made, but advance planning and decisions would have helped.

Julia, daughter / carer

What is an Advance Statement of Preferences?
An Advance Statement is a document that sets out what you would like to have happen as you approach the end of your life, if you become unable to communicate or make decisions for yourself.

Is an Advance Statement a legal document?
An Advance Statement is not a legal document but those caring for you will be expected to follow your wishes where practicable.

Is this where I can refuse medical treatment?
No, you can do that with an Advance Decision - see next section. This is more about your beliefs, values and other things that are important to you, plus some practical information.

Who can help me with this if necessary?
We recommend that you have a conversation with a healthcare professional to understand the kind of choices you might wish to make.

Can I change my Advance Statement?
Absolutely. Your wishes and priorities may change over time, some things that seem important now may be less so in the future. We recommend you review this on a regular basis.

What should I do with it?
Discuss it with your family and find a way to ensure it is available when needed – more on this below and in Factsheet on page 57.

Other names used
Advance Statement, Preferred Priorities

There are a variety of forms available to create an Advance Statement and you may already have one prepared. If so, there's no need to create another.

continues...

Advance Statement *contd.*

If you are creating this Advance Statement on behalf of someone else, for example if you hold lasting power of attorney or are a close family relative, take care to reflect what they would have wanted, which is not necessarily the same as what you would like for them.

Some questions to help you decide what is important to you:

- *I do / do not wish to be kept fully informed about my condition.*
- *I do / do not wish to have a say in any decisions regarding my care.*
- *I do / do not want to know how long the doctors think I have left to live.*
- *I do / do not believe that quality of life is more important than quantity.*
- *I do / do not want to be taken to hospital if I have a potentially life-threatening situation.*

See the Factsheet on page 51 for further information on where to receive end-of-life care.

Further reading:
See NHS pages online: https://www.nhs.uk/conditions/end-of-life-care/advance-statement/

Action List

- [ ] Have a conversation with a healthcare professional.
- [ ] Use the template on the following page to create an Advance Statement, or charities such as My Living Will provide an online service: https://www.mylivingwill.org.uk/
- [ ] Ask your GP to a) keep a copy of your Advance Statement with your medical records and b) refer to it in your Summary Care Record.
- [ ] Consider other ways of ensuring your Advance Statement can be accessed and viewed. See the Factsheet on page 57.
- [ ] Review your Advance Statement from time to time to ensure it continues to reflect your wishes.

My Advance Statement of Preferences

My name is: My date of birth:

My address:

The person with lasting power of attorney (if I have appointed one) for my health and welfare is:

Name: Tel No:

Address:

Relationship to me:

Other people (friends / family) involved in my care:

Name: Tel No:

Relationship to me:

Name: Tel No:

Relationship to me:

My first language is: ☐ I need an interpreter

About my eyesight:

☐ Partially sighted ☐ Registered blind ☐ I wear glasses ☐ Contact lenses ☐ Able to read

About my hearing:

☐ I am hard of hearing ☐ I wear a hearing aid ☐ I use sign language ☐ I lip read ☐ I hear well

About my mobility:

☐ I use a stick ☐ I use a frame ☐ I use a trolley ☐ I need an arm to hold on to
☐ I use a wheel chair ☐ I walk without assistance

Other general information about my health:

contd.

When and if I require care, I would like to be cared for...

☐ at home ☐ in a care home ☐ I don't mind

When I require end of life care, I would like to be cared for...

☐ at home ☐ in a care home ☐ in hospital ☐ in a hospice ☐ I don't mind

What my priorities are when I approach my end of life...

What you might include here (see also the questions on page 30):

- Whether it is important that you live as long as possible, or maximise the quality of life for the time you have left.
- The people you'd like to be with you.
- Any religious faith or cultural practices that you'd like observed, or particular music.
- Anything you'd like in the room: aromatherapy smells, fresh flowers, family pictures.
- Arrangements made regarding, for example, the care of your pet(s).

☐ I have created a Mycarematters Profile / other form outlining my needs and preferences.

☐ I have created an Advance Decision to Refuse Treatment (ADRT).

☐ I have created a Do Not Attempt Resuscitation (DNACPR).

I have discussed the contents of this Advance Statement with this healthcare professional:

Name / role:

I am happy for the information in this Advance Statement to be shared with all healthcare professionals involved in my care.

My signature: Date:

or:

I am signing on behalf of the person named at the top of this form.

Signature: Date:

Relationship / role:

I have reviewed / amended this document:

Signed: Date:

Signed: Date:

Advance Decision to Refuse Treatment (ADRT)

"Knowing that I won't be kept alive if I've reached the stage where my body is shutting down is a great relief for me, and it's good to know that my family know exactly what I want."

Neil, fit and healthy, 66 years old.

What is an ADRT?
An Advance Decision to Refuse Treatment allows you to write down any treatments that you don't want to have in the future. This will only come into force if you lose capacity to make your own choices.

Should I have an ADRT?
If there are circumstances in which you would not wish to be kept alive, an ADRT ensures that your medical team will follow your wishes, regardless of others' opinions.

Who can help me with this if necessary?
It is advisable to discuss this with a healthcare professional; they may have a form on which to record your decisions or there are online resources to create your own, see below.

Is an ADRT a legal document?
An ADRT is legally binding if you have signed it, had your signature witnessed and have met other considerations. See link under Further Reading for more information.

Other names for an ADRT
Living Will, Advance Directive

An ADRT is legally binding and must be respected by those providing your medical care even if other people believe it is not in your best interests.

You cannot use an ADRT to demand specific treatments or ask for assistance to end your life.

Examples of circumstances in which you may wish treatments to be withheld or withdrawn:

- If you have an incurable and irreversible terminal condition that will result in your death within a relatively short time

continues...

Advance Decision to Refuse Treatment (ADRT)
contd.

- If you are diagnosed as persistently unconscious and, to a reasonable degree of medical certainty, will not regain consciousness
- If you are diagnosed as being severely and permanently mentally impaired

If you have a condition like dementia, you may want to be specific about the circumstances in which you wish to refuse life-sustaining treatment. For example, if you are unaware of your surroundings, are unable to recognise people close to you, are persistently anxious or agitated, are unable to attend to your personal hygiene, are unable to swallow, are unable to interact with others, or other circumstances.

Examples of specific treatments you may wish to refuse:

- Life support or other life-prolonging treatment
- Tube feeding
- Cardiopulmonary resuscitation in the event of cardiac arrest
- Active treatment for a separate condition unless it appears to cause you undue suffering

Remember that your Advance Decision will only come into effect if you lack capacity. If you are still able to make decisions about medical treatment, your Advance Decision will not apply.

Further reading:
https://www.nhs.uk/conditions/end-of-life-care/advance-decision-to-refuse-treatment/

Action List

- [ ] Use the planner on the following page to make a note of your current thinking
- [ ] Have a conversation with a healthcare professional and/or solicitor
- [ ] Complete the form they provide or create your ADRT online with My Living Will: https://www.mylivingwill.org.uk/
- [ ] Ask your GP to a) keep a copy of your ADRT with your medical records and b) refer to it in your Summary Care Record.
- [ ] See the Factsheet on page 57 for options available to store and share your documents.

Advance Decision to Refuse Treatment Planner

My name: My date of birth:

My address:

In the following circumstances (see pages 33-34):

I wish to refuse the following specific treatments (see page 34):
(if you wish to refuse a treatment that is or may be life-sustaining, you will need to state: 'I am refusing this treatment even if my life is at risk as a result'.)

For the avoidance of doubt, you might state that you wish to receive medical treatment for any symptoms such as violent or degrading behaviour or if you appear to be in pain, even if that should worsen your physical condition or shorten your life.

You will need to:
a) talk through the options with a healthcare professional
b) complete a form and sign
c) have your signature witnessed.

Do Not Attempt Resuscitation (DNAR, also known as DNACPR and, previously, DNR)

"Talking about death does not make it more likely to happen."

Patricia Brayden, Medical Director, St Catherine's Hospice, Crawley

What is a DNAR form?
DNAR stands for Do Not Attempt Resuscitation; also described as DNACPR: Do Not Attempt Cardiopulmonary Resuscitation (CPR). A DNAR form is an instruction to healthcare professionals **not** to perform CPR.

What is CPR?
CPR involves rapid, repeated compression of a person's chest, blowing air or oxygen into their lungs, if necessary by inserting a tube into their windpipe, delivery of high-voltage electric shocks through their chest and injection of drugs into the neck. These interventions are taking over the role of the person's heart and lungs to pump blood and oxygen around their body.

Why should I complete a DNACPR form?
At a certain stage in our lives and/or illness we reach a point where CPR has an almost zero chance of success. At best, it may prolong our life for a few hours or days on life support machines. So, if our heart and breathing stop and CPR is attempted, it subjects us to an extremely vigorous physical intervention that may deprive us and those important to us of a dignified death. In other words, it may merely prolong the process of dying and, in doing so, prolong or increase suffering. Without a DNACPR in place healthcare professionals (including ambulance staff) are required to attempt CPR.

Is a DNACPR a legal document?
A DNACPR is not a legally binding document. If you wish to record your decision in a legal document you can describe your decision not to receive CPR in your ADRT. However, a DNACPR properly completed and signed by a healthcare professional will be respected by those attending to your medical needs.

What does a DNACPR cover?
A DNACPR form **only** covers CPR, so **even** if you have a DNACPR in place you'll still be given all other types of treatment for your condition as well as treatment to ensure you're comfortable and pain-free.

continues...

"What leads up to our last moments varies for each of us but what we all share in common in dying is that, as a last event, our hearts will stop, bringing an end to our life. Technically, therefore, each of us will have suffered a cardiac arrest. In our hospital system, should that final event be noted, someone will perform CPR unless there is a DNACPR form (Do Not Attempt Cardio Pulmonary Resuscitation) in place. "Terrible physical trauma will be inflicted on the recently dead person and psychological trauma on the family, friends, other patients, and the ward and resuscitation staff. Sadly, none of these clinically frail individuals could ever survive CPR. We need to ensure that all of us – patients, families, friends, nurses, doctors, administrators and legislators – accept that the end of natural life is characterised by "the end of living, heart stopping, dying".

Dr Gordon Caldwell

Who can help me with this?
A DNACPR needs to be signed by a healthcare professional and they will not do so unless they believe it to be in your best interests.

Can my family create a DNACPR on my behalf if I do not have capacity to do so?
Your 'next of kin' or other family members do not have the right to put a DNACPR in place for you. Your lasting power of attorney can act on your behalf and ask a healthcare professional to sign a DNACPR.

Can anyone else create a DNACPR for me?
If you live in a care home the manager may discuss it with you (or your family if you no longer have capacity) and your GP and create one as a decision taken in your best interests.
If you are admitted to hospital your healthcare team may put a DNACPR in place, again based on a decision taken in your best interests and in consultation with your lasting power of attorney and/or your family.

It is important to understand that this form only covers CPR, so even if you have a DNACPR in place you'll still be given all other types of treatment for your condition as well as treatment to ensure you are comfortable and pain-free.

Action List

- [ ] Discuss this with a healthcare professional to establish whether and when it will be appropriate for you to have a DNACPR in place.
- [ ] Complete and sign the form - your medical team will use a form recognised in your area.
- [ ] See the Factsheet on page 57 for suggestions on how to ensure it is available when needed. **Note that photocopies are not recognised as valid.**

Allow a Natural Death: Do Not Attempt CPR

My name is: My date of birth:

My address:

In the event that my heart stops I do not want anyone trying to re-start it by doing CPR.

This decision has been taken by me (named above) and/or the following person / people

Name	Relationship / Role

☐ If I have been unable to participate in the discussion leading to this decision, please ensure that my family / carers are aware that a DNACPR has been put in place for me, and explain why.

This section to be completed by a senior healthcare professional.
I am proposing / supporting this decision because:

Signed by senior healthcare professional (print name):

Signature: Date

Reviewed.
Signature: Date:

Organ and/or Tissue Donation

Do you wish to donate your organs and/or tissue?
Choosing to donate your organs is a generous and worthwhile decision that can save lives; you can control whether you donate all, some or none.

Being an organ and tissue donor is becoming the default position from spring 2020 in England. If you want to be sure your wishes are followed, you are advised to register.

NHS Blood and Transplant run the Organ Donor Register. Register via the QR code or with this link: https://www.organdonation.nhs.uk/register-your-decision/ or call 0300 123 23 23.

Do you wish to donate your brain for medical research?
Donating your brain is managed by The Medical Research Council. Contact the nearest brain bank to where you live to obtain information about registration. In most cases it will be possible to register with your nearest brain bank.

Fnd your nearest brain bank here:
https://mrc.ukri.org/about/getting-involved/taking-part-in-medical-research/or call 01793 416200

Action List

- [ ] Consider whether you wish to donate all, any or none of your organs or tissue after your death
- [ ] If you wish, register with the appropriate organisation
- [ ] Inform your family and record your decision in your Advance Statement. (Just leaving instructions in your Will risks your wishes not being met as it might not be read in time: donation is time-sensitive.)

Funeral Preferences

"My husband comes from a naval background and loves the sea, so I always assumed he'd want his ashes scattered at sea. I was really surprised when he said he wanted his ashes buried in the churchyard with mine (when my time comes!) - thank goodness we talked about it!

Jan, wife and carer, West Sussex

What is this for?
This form enables you to write down your preferences for the kind of send-off you'd like.

Who can help me with this if necessary?
You might like to discuss what you want with your family and/or friends, perhaps ask them to get involved with ideas for the kind of event they believe would best reflect who you are.

Is this a legal document?
This form is not a legal document; you can include instructions regarding your funeral in your Will if you prefer.

Why should I complete this form?
It's entirely optional, some people prefer not to think about it, others like to leave detailed instructions. However, if it matters to you at all, don't assume your family know what you'd like!

What shall I do with it?
Keep it with a copy of your Will, or somewhere that you know your family will find it. You may wish to review it from time to time.

Funerals have moved on a lot in recent years; many funeral directors cater for non-religious ceremonies and there tends to be more of a focus on celebrating someone's life as opposed to mourning their departure. Ceremonies are becoming increasingly personalised with some families choosing to lead the service.

This is an opportunity for you to help your family at a difficult time feel confident that they are doing things just the way you'd like it.

Action List

- [ ] Complete as much or as little of the form as you wish.
- [ ] Keep a copy with your Will or somewhere where your family will find it.

My Funeral Preferences

Do you want to be cremated or buried?

If cremated, what would you like to be done with your ashes ie kept or scattered?

If buried, where would you like to be buried?

Would you prefer a religious or secular (non-religious, humanist) ceremony?

Do you have a location in mind?

What music would you like played, which hymns or songs would you like to be sung?

Which poems, prayers or readings would you like?

Are there people you'd like to read the poems, prayers or readings?

Have you prepared a list of people you'd like notified? If so, where is it?

Do you want a large ceremony or something small for direct family only?

continues...

My Funeral Preferences *contd.*

Would you like flowers or to ask people to donate to a particular cause?

Who would you like to organise your funeral?

How will your funeral be paid for? (savings / my estate / pre paid funeral plan / insurance policy / with government support / I don't know)

Any other thoughts?

Factsheet

Advance Care Planning

Advance Care Planning means different things to different people, ranging from a casual chat with a family member or friend, to generating a suite of documents to cover every eventuality.

For the purposes of this document we suggest that an Advance Care Plan comprises a Mycarematters Profile, Advance Statement, Advance Decision and Lasting Power of Attorney for Health and Welfare. In this way, you will have set out your preferences for both the medical and non-medical aspects of your future care.

It is of course entirely your choice as to which, if any, of these documents you wish to complete. Any of the versions offered in this Handbook can be replaced with alternatives.

Tick the documents you have completed which together form your Advance Care Plan:

- ☐ Mycarematters Profile (or alternative)
- ☐ Lasting Power of Attorney – Health and Wellbeing
- ☐ Advance Statement of Preferences
- ☐ Advance Decision to Refuse Treatment (ADRT)
- ☐ Do Not Attempt Cardiopulmonary Resuscitation (DNACPR)
  (you may wish to complete this later and add it when appropriate)

Do not wait until you have completed all documents to share them with, for example, your GP. It is fine not to attempt to complete everything in one go.

Note: advance care planning is a wide-ranging and complex subject; it is unreasonable to expect all healthcare professionals to be familiar with all aspects, especially regarding what is and isn't a legal document and what should or need not be signed and by whom. You should find those answers within this Handbook but what we cannot replicate here is the expertise of lawyers or healthcare professionals in guiding you as to the most appropriate course of action for your particular circumstances.

Factsheet

Financial Planning

Paying for care

What you will have to pay for care will vary depending on the area that you live in, plus your own personal financial circumstances. Your local council must calculate the cost of your care and how much you have to contribute from your resources.

If you have over £23,250 in capital you will have to pay for your own care. You may wish to speak to a financial adviser to understand the options available to you to meet the costs of care in the most efficient manner according to your circumstances.

Further information: https://www.ageuk.org.uk/information-advice/care/paying-for-care/paying-for-a-care-home/

Funeral Plannng

The cost of a funeral depends very much on the choices you make. On one end of the scale, you can pay for horses, fancy coffins, marble headstones – whatever you can imagine; while on the other, you could just have a direct cremation and arrange the funeral yourself.

However you plan to do it, many people worry that when they die, they won't leave enough money for their funeral, burdening their loved ones with the cost.

With a funeral plan, you arrange and pay for it in advance, so your relatives don't have to cover all the cost themselves.
Link: https://www.moneyadviceservice.org.uk/en/articles/funeral-plans

Inheritance Planning

Careful Inheritance Tax (IHT) planning is all about passing as much of the proceeds of an estate as possible to chosen beneficiaries rather than to HMRC. It is also about maintaining flexibility and control over any arrangements that are made.

As with all financial planning, if you believe you will be effected by inheritance tax you may wish to speak to a financial adviser.

Finding an adviser

SOLLA (Society for Later Life Advisers) can help you find a local adviser: https://societyoflaterlifeadvisers.co.uk/ or phone 0333 2020 454. The Financial Conduct Authority offers some useful tips: https://www.fca.org.uk/consumers/finding-adviser

Factsheet

Keeping Fit

The NHS advises us all to do some type of physical activity every day. Any type of activity is good for you and the more the better.

Specifically for people over 65 they recommend:

- aim to be physically active every day. Any activity is better than none. The more you do the better, even if it's just light activity.
- do activities that improve strength, balance and flexibility on at least 2 days a week.
- do at least 150 minutes of moderate intensity activity a week or 75 minutes of vigorous intensity activity if you are already active, or a combination of both.
- reduce time spent sitting or lying down and break up long periods of not moving with some activity.

If you've fallen or are worried about falling, doing exercises to improve your strength, balance and flexibility will help make you stronger and feel more confident on your feet. Speak to your GP if you have any concerns about exercising.

Examples of light activity (any kind of movement as oposed to sitting or lying down) :
getting up to make a cup of tea - moving around your home - walking at a slow pace - cleaning and dusting - vacuuming - making the bed - standing up

Examples of moderate intensity activities (raising your heart rate, and making you breathe faster and feel warmer):
brisk walking - water aerobics - riding a bike - dancing - doubles tennis - pushing a lawn mower - hiking

Examples of vigorous intensity activity (making you breathe hard and fast):
jogging or running - aerobics - swimming fast - riding a bike fast or on hills - singles tennis - football - hiking uphill - energetic dancing - martial arts

Examples of activities that strengthen muscles:

carrying heavy shopping bags - yoga - pilates - tai chi - lifting weights - working with resistance bands - doing exercises that use your own body weight, such as push-ups and sit-ups - heavy gardening, such as digging and shovelling.

For further information use the QR code or the following link:
https://www.nhs.uk/live-well/exercise/physical-activity-guidelines-older-adults/

Factsheet

Healthy Eating

Along with physical exercise, what we eat can help stave off age-related conditions including cardiovascular disease and cognitive decline. Eating the right food can also help to protect oral and dental health, and bone and joint health in later life.

No single food provides all the nutrients we need, so it is important to include a wide variety of foods in the diet.

The Eatwell Guide splits food into four main groups:

- Fruit and vegetables should make up over a third of the food we eat each day. Aim to eat at least 5 portions of a variety of fruit and veg each day. Choose from fresh, frozen, tinned, dried or juiced.
- Potatoes, bread, rice, pasta and other starchy foods should make up just over a third of the food we eat.
- Dairy and alternatives: Milk, cheese, yoghurt and fromage frais are good sources of protein and some vitamins, and they're also an important source of calcium, which helps keep our bones strong. Go for lower fat and lower sugar products where possible: 1% fat milk, reduced-fat cheese or plain low-fat yoghurt.
- Beans, pulses, fish, eggs and other proteins: Choose lean cuts of meat and mince, eat less red and processed meat like bacon, ham and sausages. Aim for at least 2 portions of fish every week, 1 of which should be oily, such as salmon or mackerel.

The ability to synthesise vitamin D by the skin decreases with age. The British Nutrition Foundation recommends that older people take a supplement containing 10 micrograms (mcg) of vitamin D daily as well as regularly eating food sources of the vitamin (for example oily fish and fortified breakfast cereals).

And let's not forget drinking: on average, water makes up 60% of our body weight, so regular fluid intake is essential for the correct functioning of all the cells in the body, particularly before, during and after exercise. Indications of not drinking enough include headache and fatigue. The Food Standards Agency recommends we drink about 6-8 glasses of fluid a day: about 1.5-2 litres.

Further reading:
The NHS's Eatwell Guide: https://www.nhs.uk/live-well/eat-well/the-eatwell-guide/

Factsheet

Housing Options

You may be adamant that you want to remain in your own home "until they carry me out in a box" as they say, and that may be the right option for you.

On the other hand, if retaining your independence as long as possible is one of your goals, you may want to consider some alternatives that increase your chances of doing just that. The choices available to you can be as modest as fixing a few grab rails in your current home, to moving to a completely different type of property.

The options available will vary from region to region, but we have included those types of housing generally available.

Staying in your own home

There are things you can do to make your house suitable for later life, for example, adding a stair lift or bath lift (or consider swapping your bath for a walk-in shower). Occupational Therapists have the expertise to advise you on appropriate modifications. Your GP or other healthcare professional may be able to refer you, or you can pay for it yourself. The Royal College of Occupational Therapists lists qualified and registered occupational therapists: access their website with the QR code or use this link: https://rcotss-ip.org.uk/find

Moving to a more suitable property / location

Whether buying or renting, this might be worth considering, perhaps to move closer to other members of your family, or nearer to shops or public transport. It might be more a question of finding a property that's easier to manage, has fewer steps or is generally easier to adapt for later life.

Multigenerational Housing

"We chose to buy a house together when my Mum was diagnosed with early onset dementia, and live as a multigenerational family. The benefits have definitely outweighed the challenges. Caring for someone has brought us together and helped us to prioritise what really matters."

Suzy, Chepstow

This is not an option that suits all families, but where it does, there are significant benefits where each generation can support the other, for example with baby sitting / child care, and reduced overall housing costs.

Housing Options *contd.*

Sheltered / Retirement Housing
Usually available to people aged 55 or more, these self-contained flats tend to have a warden / manager on site, an alarm system, communal areas and may offer social activities.

Assisted Living / Extra Care Housing
"My Mum thought she'd hate moving to an assisted living flat but once she had settled in to her light and spacious apartment she soon came to appreciate the balance of privacy and socialising that was within her control. As a family, we had peace of mind that she was supported with carers in the building, and she was getting a hot meal every day."
Sarah, West Sussex

As with retirement housing you still have your own front door, but staff are usually available up to 24 hours per day to provide personal care and support services. These can include help with washing, dressing, going to the toilet and taking medication. Domestic help, such as shopping and laundry, and meals may also be provided.

Shared Lives Schemes
Shared lives schemes support adults with needs that make it harder for them to live on their own. The schemes match someone who needs care with an approved carer. The carer shares their family and community life, and gives care and support to the person with care needs. Some people move in with their shared lives carer, while others are regular daytime visitors. Some combine daytime and overnight visits.

Care Homes
Care homes is a catch-all term used for Nursing homes and Residential homes. See more in the Factsheet on page 49.

Further reading:
Age UK offer tips on how to make your home more comfortable: Access their website via the QR code or use this link: https://www.ageuk.org.uk/information-advice/care/housing-options/adapting-home/making-home-comfortable/

The Elderly Accommodation Counsel have a useful questionnaire to help you think about different aspects of your home and how you live in it. Access the questionnaire via the QR code or use this link: https://hoop.eac.org.uk/hoop/start.aspx

Factsheet

Types of Care

Care Homes
Care homes in England are required to be registered with the Care Quality Commission (CQC) which monitors, rates and inspects services and can range in size from 4 beds to over 100. They tend to be run by private companies (who may own one or many) or charities and a few are run by local councils.

There are broadly two types of care home:

Residential Homes
Residential homes provide help and assistance with personal care, but do not have nurses on the care team.

Nursing Homes
Nursing homes provide help and assistance with personal care and also have professional registered nurses and experienced care assistants who provide 24-hour nursing care services for people with more complex health needs.

Some care homes offer both residential and nursing home places.

In addition to being registered to provide general nursing care, many nursing homes also offer rehabilitation services which include different therapies, such as physical, speech and pain therapies and specialist health care including dementia care and palliative care. These homes tend to be for people who are very frail or for people who are unable to care for themselves and have complex health care requirements.

Contact the CQC to find a care home and check the quality of their care: https://www.cqc.org.uk/what-we-do/services-we-regulate/find-care-home or call 03000 616161.

Care at home
Home care agencies, also known as domiciliary agencies, care for you in your own home with support ranging from one 15 minute visit a week to live-in round-the-clock care.

Types of Care *contd.*

Agencies are required to be registered with CQC if they provide personal care. Agencies providing shopping, laundry and similar services but no personal care do not need to be registered with the CQC.

Contact the CQC to find care in the home services and check the quality of their care: https://www.cqc.org.uk/what-we-do/services-we-regulate/find-services-offering-care-home

Hospice care
Hospices provide care for people with a life-limiting condition as they approach the end of their life, but sometimes also earlier in a person's illness when symptoms are difficult to manage. They deliver hospice care for many more people in their own home or in a care home than in the hospice itself and are happy to advise other healthcare teams looking after people at end of life.

Hospice care places a high value on dignity, respect and the wishes of the person who is ill. It aims to look after all their medical, emotional, social, practical, psychological, and spiritual needs, and the needs of the person's family and carers. Care also extends to those who are close to the patient, as well as into the bereavement period after the patient has died.

Further reading:
Which? Later Life Care offer a tool to find out about care home fees, paying for home care and eligibility for financial support: https://www.which.co.uk/later-life-care/financing-care/cost-of-care-and-eligibility-checker

If you hold power of attorney and are considering these options on behalf of someone else, be sure you understand your legal responsibilities; take legal advice if uncertain.

Factsheet

Where to receive end-of-life care

This may not be something you need or want to think about now, but the options available are here when you'd like to know more.

The options
You can record your preference for where you would like to receive end-of-life care in your Advance Statement. Where we die is not always within our control but your care team will do their best to meet your wishes if practicable.

It is quite possible that you change your mind when the time comes and that's absolutely fine. Just having the conversation about the options available with family members and/or a healthcare professional might help answer other questions you may have.

There may come a time when you might prefer not to be transferred to hospital for treatment, even if it means an increased risk of dying, to avoid the confusion and distress that can be caused by a stay in hospital. Talking this through with a healthcare professional in advance and writing it down means your wishes are more likely to be seen and followed through.

If your health is deteriorating quickly and you're nearing the end of your life, you should be considered for the NHS continuing healthcare fast-track pathway, so that an appropriate care and support package can be put in place as soon as possible – usually within 48 hours. Your preferred location will be taken into account and treatments like pain relief to keep you comfortable can usually be delivered in most settings.

At home
Many people like this option, wishing to be in familiar and calm surroundings with no restrictions on when your family and friends can be with you. Your care needs may well dictate whether this is a suitable option for you, and what support is available from health and social care services and/or your local hospice.

You may like to consider employing the services of a doula: their role is not to replace medical services but to support people to live their life as meaningfully as possible right to the end, while making it more comfortable and natural for them to die at home if they want to. Living Well Dying Well offer training for doulas

Where to receive end-of-life care *contd..*

and can put you in touch with doulas in your area: https://www.lwdwtraining.uk/about-livingwell-dyingwell/

Hospital
Hospitals are busy places and not generally the ideal environment for end-of-life care. Despite this, almost half of deaths still take place in hospitals. Most hospitals have specialist palliative care teams who specialise in controlling symptoms, and some have palliative wards offering a more peaceful environment.

Care Home
If you are already a care home resident this is likely to be your preferred option as the staff will be familiar with your needs. Good care homes will have trained their staff to engage sensitively and respectfully with dying residents, and will work closely with healthcare professionals to avoid unnecessary hospital admissions.

If you are not a resident but would like to receive end-of-life care in a care home this may be possible but there is likely to be a cost involved unless it is covered by NHS continuing healthcare.

Hospice
Traditionally, hospices focused on palliative care for people with cancer but now, anyone diagnosed with a life-limiting condition is eligible for hospice care. However, as the service is delivered by charities and not by the NHS there is no guarantee they will have a bed available. They may still be able to provide you with hospice care in your own home.

Hospices are often calm places, decorated in a more homely way than a hospital. Visiting times, meal times and treatment times are usually very flexible. The staff's main aim is to allow you to die in comfort and with dignity. They are experts in controlling symptoms and side effects that can be common in the last few weeks of life.

Find your local hospice: https://www.hospiceuk.org/about-hospice-care/find-a-hospice

Factsheet

Bereavement and Grief

What is grief?
Grief is a natural response to loss. It's the emotional suffering we feel when something or someone we love is taken away and is commonly experienced by people who receive a terminal diagnosis. We may experience all kinds of difficult and unexpected emotions, from shock or anger to disbelief, guilt, and profound sadness. The pain of grief can also disrupt our physical health, making it difficult to sleep, eat, or even think straight. These are normal reactions to loss.

The grieving process
Grieving is a highly individual experience; there's no right or wrong way to grieve. How we grieve depends on many factors, including our personality and coping style, our life experience and our faith.

The grieving process takes time - there is no "normal" timetable for grieving. Whatever our grief experience, it's important to be patient with ourselves and allow the process to naturally unfold.

The stages of grief
In 1969, psychiatrist Elisabeth Kübler-Ross introduced what became known as the "five stages of grief." These stages of grief were based on her studies of the feelings of patients facing terminal illness.

The five stages of grief

Denial: "This can't be happening to me."
Kübler-Ross viewed this reaction as a type of shock absorber, necessary in order to deal with the devastating news. Denial is for the most part a temporary defense, one that gives expression to the hardship entailed in coping with reality. Denial lets us cope with only what we can handle.

Anger: "Why is this happening? Who is to blame?"
For the person who has experienced a great loss and for people in the terminally ill patient's environment, this is a particularly difficult stage to deal with. Our anger is directed outward to family members, healthcare professionals and friends. At times it may seem arbitrary and indiscriminate. However, it is important to remember that underneath the anger is pain.

Bereavement and Grief *contd.*

Anger provides structure, one that replaces the structure lost with a diagnosis. It gives us a way to still feel connected to those around us at a time when we are feeling lost.

Bargaining: "Make this not happen, and in return I will..."
This stage is characteristic of terminally ill patients who are coping with the inevitability of impending death and with gradual loss. We try to delay the end by bargaining with an external force, in an attempt to avoid the unavoidable.

The bargain generally entails a "payment" in exchange for a postponement of the sentence, or a fulfillment of last wishes. We may also bargain about things like pain, whether physical or emotional.

It is important to remember that guilt often comes along with bargaining. We often go down the path of "What if.." or "If I only...", finding fault in ourselves and things we have done.

Depression: "I'm too sad to do anything."
This step focuses on a deep sense of loss, it is felt in varying degrees from person to person. Depression replaces the anger and the attempts at bargaining. With it comes forlorn thoughts of the future, feelings of guilt and shame, failure and regret.

Kübler-Ross does not advise trying to cheer up or calm the individual steeped in depression. It is not worth trying to encourage feelings of "all will be well." She claims that feelings of depression are an important part of the emotional process, and that it facilitates progress towards acceptance and peace. We all need compassion and understanding to help us through this stage.

Depression is an important part of the grief process. When faced with a loss, it would be unusual not to experience depression.

Acceptance: "I'm at peace with what's happening."
Acceptance is the final stage. It is about accepting the new reality.

In this stage we cease our fight against fate, letting go of all personal battles with our past and surroundings. At this point,

continues...

Bereavement and Grief *contd.*

we are able to express the various feelings experienced in the previous stages, and can come to terms with mortality and with the need to part from loved ones.

Not everyone goes through all five stages of grief and certainly not all people go through the stages in the same order. For some of us certain stages may last only minutes or hours.

If you are experiencing any of these emotions following a loss, it may help to know that your reaction is natural and that you'll heal in time. If you do go through these stages of grief, you probably won't experience them in a neat, sequential order, so don't worry about what you "should" be feeling or which stage you're supposed to be in.

Further reading:
https://www.helpguide.org/articles/grief/coping-with-grief-and-loss.htm

Factsheet

Understanding mental capacity

If you are thinking about making a particular decision on someone else's behalf, you must first check whether or not they can make that decision for themselves, at the time it needs to be made.

There are circumstances in which mental capacity can come and go (for example, with dementia and some mental illnesses). A person can also recover mental capacity (for example, following a severe stroke).

They can make the decision in question if they can:

- understand the information they need - for example, what the consequences will be
- remember the information for long enough to make the decision
- weigh up the options and make a choice
- communicate their decision in any way – for example, by blinking or squeezing a hand
- You cannot decide a person lacks mental capacity because you think they've made a bad or strange decision.
- If the person cannot make a decision at a certain time, they may still be able to:
  - make it at another time
  - make decisions about other things

Do not make a decision for them if it can wait until they can do it themselves.

You can ask the person's doctor or another medical professional to assess their mental capacity. They are expected to follow the Mental Capacity Act code of practice when checking mental capacity.

Further reading:

Carer's Guide to the Mental Capacity Act: https://www.carechartsuk.co.uk/wp-content/uploads/2017/02/mcaguide-final.pdf

The Mental Capacity Act Code of Practice: https://www.gov.uk/government/publications/mental-capacity-act-code-of-practice, providing guidance for people with power of attorney or working with people who are unable to make decisions for themselves.

Factsheet

Where to store your documents

Whilst there is value in a discussion about your wishes for your future care, those wishes are much more likely to be met if you record them in an appropriate document, and then ensure they are available when required.

- Provide your GP with copies of your Advance Statement, your Advance Decision to Refuse Treatment and your DNACPR (or similar documentation created with a healthcare professional). You should keep the originals.
- With your consent this information can be added by your GP to your Summary Care Record, an electronic record that can be accessed by many healthcare professionals.
- If you have created an online Mycarematters record, certain documents can be uploaded and stored alongside your needs and preferences. Other documents can be referred to and you can say where / with whom it is stored. This information can then be accessed via any internet-linked device. To enable healthcare professionals to access your information they need your unique Mycarematters code. Options such as key fobs and luggage tags with your code printed on it are available: https://www.carechartsuk.co.uk/product-category/mycarematters/ or call 01403 210485.
- Your local area might operate an Electronic Palliative Care Coordination System (EPaCCS) in which case your medical team will ensure that your details are added when appropriate.
- The Lions' Message in a Bottle (kept in the fridge) is popular in some areas as a method of ensuring your information is available to those providing you with emergency care.

Storing a Will

It is not generally recommended that you keep an original Will at home. If you have a fire, flood or burglary, you risk losing your Will. If your Will is damaged in any way, then the courts could declare the Will invalid. If you wish to keep your documents at home, consider at least buying a fire and waterproof container.

If your Will has been drawn up by a lawyer they are likely to offer you free storage and provide you with a copy.

The National Will Safe Document Storage facility is a national, central, storage facility for Wills. Your Will and any other relevant legal documents, such as Powers of Attorney, are kept in a waterproof wallet in a specialist document archive facility.

Glossary of Terms

Attorney(s)	The person / people you appoint in your Lasting Power of Attorney document to make decisions when you have lost the capacity to do so yourself.
Best Interest Decisions	All decisions made on your behalf when you do not have the capcity to make decisions for yourself must be made in your best interests.
Capacity	To have capacity means that you are able to make important decisions for yourself (even though those decisions might be thought to be unwise by those around you!). Establishing whether someone has capacity is set out in the Mental Capacity Act. Having a diagnosis of a condition such as dementia does not mean that you do not have capacity. See Factsheet on page 56.
Deputy	A person appointed by the Court of Protection to make decisions on your behalf and in your best interests if you have not appointed Attorney(s). Previously known as a receiver.
Donor	The person making a power of attorney is called a donor.
Mental Capacity Act	A legal framework designed to protect and empower people who may lack the mental capacity to make their own decisions about their care and treatment.
OT (Occupational Therapist)	A health/social care professional providing practical support to people needing support to remain independent and/or carry out day-to-day activities.
Palliative Care	A non-invasive approach to care prioritising comfort over cure.
Probate	The process by which a Will is accepted as a valid public document.
Summary Care Record	An electronic patient record held on a central NHS database, generated by the GP's record.

Further help and resources

The following national organisations may be able to provide further information or support, at either national or regional level.

Age UK	https://www.ageuk.org.uk	0800 678 1602
Alzheimer's Society	https://www.alzheimers.org.uk	0330 333 0804
British Nutrition Foundation	https://www.nutrition.org.uk/	020 7557 7930
Care Charts UK	https://www.carechartsuk.co.uk/	01403 210485
Carers UK	https://www.carersuk.org/	0808 808 7777
Carers Trust	https://carers.org/	0300 772 9600
Care Quality Commission	https://www.cqc.org.uk/	03000 616161
Citizens Advice Bureau	https://www.citizensadvice.org.uk/	03444 111 444
Compassion in Dying	https://compassionindying.org.uk	0800 999 2434
Dementia UK	https://www.dementiauk.org	0800 888 6678
Digital Legacy Association	https://digitallegacyassociation.org	020 8133 8116
Dying Matters	https://www.dyingmatters.org	08000 21 44 66
Eatwell Guide	https://www.nhs.uk/live-well/eat-well/the-eatwell-guide/	
Elderly Accommodation Counsel	http://www.eac.org.uk/	
Financial Conduct Authority	https://www.fca.org.uk/consumers/finding-adviser	
Gov.UK	https://www.gov.uk/attendance-allowance	0800 731 0122
	https://www.gov.uk/carers-allowance	
	https://www.gov.uk/inheritance-tax	
	https://www.gov.uk/power-of-attorney	
Healthwatch	https://www.healthwatch.co.uk	03000 683 000
HelpGuide.org	https://www.helpguide.org/	
Hospice UK	https://www.hospiceuk.org	020 7520 8200
Living Well Dying Well	https://www.lwdwtraining.uk/about/	01273 474278
Marie Curie	https://www.mariecurie.org.uk	0800 090 2309
Medical Research Council	https://mrc.ukri.org/	
Mycarematters	https://mycarematters.org	01403 210485
Mydecisions.org.uk	https://mydecisions.org.uk/	
My Living Will	https://www.mylivingwill.org.uk/	
National Will Register	https://www.nationalwillregister.co.uk/	0330 1003660
NHS Mental Capacity Act	https://www.nhs.uk/conditions/social-care-and-support-guide/making-decisions-for-someone-else/mental-capacity-act/	

continues...

Further help and resources *contd.*

Office of the Public Guardian	https://www.gov.uk/government/organisations/office-of-the-public-guardian	0300 456 0300
Organ Donation	https://www.organdonation.nhs.uk/	0300 123 23 23
Play List for Life	https://www.playlistforlife.org.uk/	0141 404 0683
Resuscitation Council	https://www.resus.org.uk	020 7388 4678
Royal College of Occupational Therapists	https://rcotss-ip.org.uk/	020 7450 2330
Shared Lives Plus	https://sharedlivesplus.org.uk/	0151 227 3499
Society of Later Life Advisers	https://societyoflaterlifeadvisers.co.uk/	0333 2020 454
Solicitors for the Elderly	https://sfe.legal/	0844 567 6173
The Law Society	https://solicitors.lawsociety.org.uk/	020 7320 5757
Which? Later Life Care	https://www.which.co.uk/later-life-care	
Which? Wills	https://wills.which.co.uk/	01992 879256

Annual reminder

Would you like us to send you an email once a year to remind you to review your decisions and make sure they still reflect your current wishes and situation?

If so, just send an email to: info@mycarematters.org with 'Annual reminder' in the subject line.

You can opt out at any time and you can make changes to any of the paperwork you have put in place at any time, without waiting for our prompt.

☐ I sent an email requesting an annual reminder on ..... / ..... / .....

☐ I do not want an annual reminder.

Notes

Names and contact details *contd.*

Name: _____

Organisation: _____

Tel No: _____

Email: _____

Visited (dates): _____

_____

Name: _____

Organisation: _____

Tel No: _____

Email: _____

Visited (dates): _____

_____

Name: _____

Organisation: _____

Tel No: _____

Email: _____

Visited (dates): _____

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Name: _____

Organisation: _____

Tel No: _____

Email: _____

Visited (dates): _____

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