MS Trust

Thinking ahead

— Setting out your wishes for your future care and treatment

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Contents

Introduction

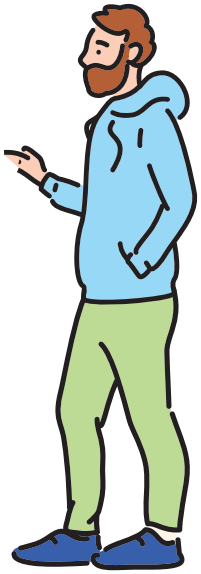
Thinking ahead

Thinking about the future can be emotionally challenging, particularly when you're living with MS. Living in the moment and not thinking or worrying about the future can be a good way to live. However, taking time to think ahead about what's important to you, and what you might want to happen if your health changes, can be a useful exercise for you and those around you.

This process of thinking about, and setting out, your wishes for your future care and treatment is known as advance care planning in England, Wales and Northern Ireland, or anticipatory care planning in Scotland; often shortened to ACP. This book gives you some guidance about what to cover if, and when, you choose to have some of these advance care planning discussions to ensure you have the best chance of your wishes being followed.

Our Helpline Team are here for you when things are getting difficult. They can provide you with information or signpost you to other sources of support. You can call them on **0800 032 3839** or email **helpline@mstrust.org.uk.**

This book contains a lot of information and it's not our intention that you need to read it all at once. We suggest you take your time and gather information at your own pace, perhaps starting with the topics that are most important to you. We've included links to further information at the end, where you can find out mo e about the legal status of your decisions in each of the devolved nations (ie where they are legally binding) and example templates for the various documents that you may find helpful to shape your decisions and make your wishes known.



1. Why plan ahead?

Your MS symptoms might not affect you much right now, but if you had a sudden worsening of your MS, or you became unwell for another reason, do you know what treatments you'd be offered? Or who'd make decisions about your care if you were too unwell to decide for yourself?

How MS affects your life is very personal, but there are some situations that are common with the condition, especially in the later stages. Talking through what might happen and what treatment options are possible with a health professional you know and trust, can increase your understanding of your condition. It can also allow you to prioritise what's important to you and help you make choices and maintain control over your life.

By sharing your thoughts with your loved ones and anyone who's closely involved with your care, before a crisis occurs, you and your loved ones can feel more prepared should a particular situation arise. Whilst these discussions may be emotional, they are worth it, and it can be very reassuring to have these plans in place. If you feel very strongly about something, especially if it's a treatment you don't want to have, this is a way to get your voice heard.

Often when going into hospital, you'll be asked about your wishes with regards to life-prolonging treatments – this is standard practice. It can be a shock to be asked these questions if you've never thought about them before. Thinking ahead and documenting your decisions may reduce the number of times you're asked the same questions.

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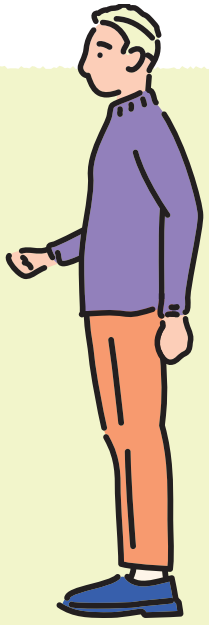


2. Starting the conversation

Anyone can raise the topic of advance care planning at any time. There's no right or wrong time to think about it. Your health professionals may suggest discussing it if there are changes in your health, or you might want to bring it up with them. You might want to start putting plans in place as soon as you're diagnosed, or you might find that you never feel ready.

Events in your life, or seeing the experience of a friend or family member, may be a trigger to think about what you might want to happen in a similar situation. It can be easier to think about medical treatments once you've experienced some of them, for example, after going into hospital. You may find that some things a e easier to discuss than others or have more relevance at different stages of your life. Some of the times that you might find yourself thinking about the future and wanting to make plans are:

- at diagnosis
- if there are significant changes in your MS
- receiving another diagnosis alongside your MS
- at retirement or if you need to stop working
- the death of someone close to you
- seeing stories in the news.

Or you may simply want the reassurance of knowing that your loved ones, and those involved with your care, are aware of your wishes.

If you're not quite sure how to start the conversation, whether it is with a family member, friend, or health or social care professional, you could try one of the following suggestions.

"I've been thinking about the future. Would you be able to help me make a plan?"

"I've heard about something called advance care planning. I think it would be helpful and would like to explore it further. What can I do?"

"Things that have happened to someone I know have made me think about the future and what I'd like to happen to me. How can I make sure people know what my wishes are?"

"I don't ever want to go back into hospital. How can I make that known?"

"I know there's no way I'd ever want [a certain treatment]. How can I make sure it never happens to me?"

"I was asked if I wanted resuscitation when I went into A&E. Is there a way I can record this decision so I don't keep being asked this?"

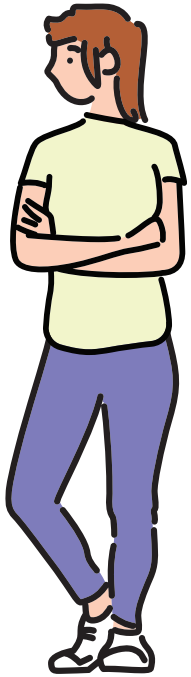
You may already have an idea of what you want in a particular situation, but thinking about things, asking questions and talking things through with your family, friends and health professionals can help you explore your options.

Advance care planning is not just one conversation. Your thoughts and wishes may change over time, and you can change your plan at any time to reflect this. Your plan can be as detailed or as basic as you'd like.

3. Making decisions about your care

Under the Mental Capacity Act (MCA) 2005, all adults in the UK are assumed to have the ability to make decisions for themselves. This includes simple decisions such as what you want to wear or eat, as well as more serious or potentially life-changing decisions about your care and treatment, like having surgery or moving into residential care. This is known as capacity.

Any illness that affects your ability to reason or communicate can potentially influence capacity. This could be on a temporary basis, for example if you lose consciousness in an accident. Or it could be more permanent, for instance if you're living with advanced dementia.



To have capacity to make a decision, you must be able to:

a) understand the information relevant to the decision
b) retain that information
c) use or weigh that information as part of the decision-making process, and
d) communicate your decision (whether by talking, using sign language or any other means).

An individual can be deemed to lack capacity if it's established that there is "an impairment of, or a disturbance in the functioning of, the mind or brain."

Unfortunately, some symptoms of MS do have the potential to affect your ability to make decisions and communicate. If this does happen it can make it difficult when thinking about complex medical treatments or weighing up the benefits versus the downsides of receiving life-prolonging treatments.

This is why it can be helpful to think and talk about sensitive situations ahead of time, so if you are ever in the position where you're unable to make decisions yourself, you can be reassured that the person making them on your behalf knows what you would or wouldn't want.

You may wish to think about situations that could cause a temporary loss of capacity, such as suddenly becoming very unwell to the extent that you can't make decisions about your treatment but where you

regain capacity as you recover. You may also want to consider the more challenging situation of what your wishes would be if you lost capacity to make certain decisions more permanently.

However, even if you have more complex health needs because of your MS, you should be supported to make your own decisions and loss of capacity must be tested for each decision that needs to be made. For example, you might have the capacity to decide what you want to drink today but might not have the ability to make more complex decisions about money.

Health professionals have a responsibility to make all reasonable efforts to support you to make decisions for yourself. For example, if you struggle to think when you're fatigued, they should try and discuss a decision at the time of day that you have the most energy.

4. What if I can't make decisions for myself?

If you're ever in a position where you're unable to decide for yourself about your care or treatment, the team looking after you will involve people close to you. They may speak to your next of kin to find out what they think you'd want in this situation, so a decision can be made 'in your best interests'.

If you want one or more people (attorney(s)) to be able to speak for you and make decisions on your behalf if you lack capacity, you can make a lasting power of attorney (LPA). This is a legal document that lets you appoint someone to help you make decisions or make decisions on your behalf, so you still have control over what happens to you.

There are two types of LPA:

- health and welfare
- property and financial affair

You can choose whether you want to have just one or both types of LPA in place and whether to have the same or different people as your attorneys for each LPA you set up. Most people appoint a family member/s or a close friend they trust.

An LPA must be registered with the Office of the Public Guardian. There is a cost to do this, but you may be eligible for a reduction or exemption if you receive certain benefits or are on a low income. If your LPA isn't registered it will not be valid and your attorney(s) won't be able to make decisions for you.

You can apply for an LPA through the government website (see further information) or you can fill in a paper form and send it through the post. You don't have to involve a solicitor but may prefer to.

Before appointing your attorney(s), you need to check that they will be willing to act for you. It's also a good idea to have a conversation about what's important to you so that they can make the decisions that you would want them to. If you make an LPA for health and welfare, you can choose whether your attorney(s) have the power to make decisions about life-prolonging treatments or not. Your attorney(s) must act in your best interests and can't be motivated to end life.

If you're appointing more than one attorney to act for you, there are three different ways that you can appoint them:

1. **Jointly** – your attorneys must make all decisions together and must agree for every decision. It's a good idea to think about how easy it is to contact your attorneys and whether this might cause a delay in your care.
2. **Jointly and severally** — your attorneys can act together, but they can also act on their own. So, if a decision needed to be made and contact could only be made with one of your attorneys, they could decide rather than having to wait until the others could also be reached.
3. **Jointly for some decisions but jointly and severally for others** – this allows you to specify when one attorney can act alone (or severally) and when decisions need to be made jointly by all your attorneys.

For several reasons it is usually better to appoint 'jointly and severally' rather than 'jointly'. If you appoint jointly, for example if you appoint two or more of your children, they must all be available at the same time to make decisions. This can be an issue if one of them is unavailable, or if one of the attorneys has died since the LPA was registered, as this makes it invalid. This could lead to delays in your care and might mean your wishes are not followed because, if you don't have capacity, you have no-one to speak on your behalf.

It can be helpful to think about, and specify, replacement attorneys at the outset of the process, so you have a back-up in the event one or more of your attorneys is unable to act or has died since your LPA was registered. The replacement attorney(s) need to be listed when the LPA is registered.

For some people a court appointed deputy may be a better option, but this comes with a fee.

You must be 18 or over and have mental capacity when you make an LPA, so it is better to put one in place sooner rather than later. It can take up to 20 weeks to register an LPA, and even longer if there are any issues or corrections that need to be made. It's important to register an LPA before it is needed, because if you no longer have the capacity to make any changes required, the application can't be processed.

The process for appointing and registering attorneys in Scotland and Northern Ireland is different to the one in England and Wales. For more details see further information.

5. What can I plan for?

ACP is an umbrella term which can include many different things, such as:

- conversations about your wishes and priorities for the future
- recording your wishes
- sharing those wishes with health professionals and people who're important to you
- appointing someone to act on your behalf if you're ever unable to make your own decisions
- refusing specific treatments in advance
- decisions about resuscitation
- making a will
- decisions about blood transfusions and organ donation
- putting in place a lasting power of attorney
- any preferences you have for your funeral.

You should involve your next of kin and people who are close to you in the discussion so they'll be aware of your wishes and can support you. You may also find it helpful to involve a health or social care professional that you trust in your discussions. Whether they're directly involved with making the plan or not, you do need to share your plan with loved ones and the health professionals involved with your care, such as your MS nurse, so your wishes can be taken into consideration.

Advance care plans can include absolutely anything that's important to you. It can be helpful to think about what you'd want the people looking after you to know if you weren't able to tell them yourself.

It might be about everyday things:

"I'm afraid of the dark, so I always sleep with a lamp on."

"I enjoy listening to music. Please can you make sure the radio is switched on in my room."

"I prefer to have a shower rather than a bath."

Or it could be something very specific or a certain situation: "I want to receive antibiotics if it's appropriate."

"I keep being told about feeding tubes and I don't want to stop eating."

"I really don't want to go into hospital if it can be avoided."

"If possible, I would prefer to be cared for and die at home when the time comes."

"I don't want to have a religious funeral."

You might want to include:

- any cultural, religious or spiritual observances that are important to you
- any dietary requirements
- the people who you'd want to be consulted about your care and to be there to support you
- where you'd prefer to be cared for, eg hospital, home or hospice, and where you'd like to die – this might be the same place or different places
- practical matters, such as who should look after children or a pet if you were unable to.

Some parts of an ACP will be very specific to you and your individual circumstances. However, there are some situations that everyone should consider including, such as how you would like to be treated and cared for if you had:

- a urinary tract infection (UTI)
- a minor infection
- infected pressure ulcers
- complications from a fall
- difficulty swallowing
- aspiration pneumonia.

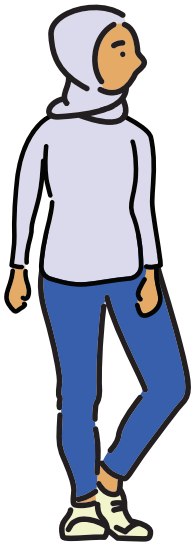
You might also want to think about what you would want to happen if your condition was deteriorating, or if you were nearing the end of life.

You can request treatment in an advance care plan, but you can't demand it. Treatment can be refused if it's not deemed clinically appropriate. You can't refuse care such as keeping you warm, clean and safe as these are considered to be basic human needs. You also can't request anything which is illegal – such as help to end your life.

6. What if there's a treatment that I know I wouldn't want?

Although you can't demand a treatment within the NHS, you do have the right to refuse a treatment.

You can include anything you wouldn't want to happen in your ACP. However, advance care plans are not legally binding. So, if you wish to refuse a specific medical treatment, you will need to have a written decision, known as an advance decision to refuse treatment (ADRT), in place. In Scotland an ADRT is known as an advance directive. To make an ADRT you must be aged 18 or over (16 or over in Scotland) and have capacity. ADRTs are also sometimes referred to as advance decisions or living wills.



An ADRT can be included in your advance care plan. In England and Wales an ADRT is legally binding, but it must be written and signed in the correct way to be followed. It's important that you specify which treatment and the specific situation in which you wish to refuse it. It must:

- state the specific treatment being refused
- state the circumstance that it's being refused in – this might be under any circumstance, or it could relate to a specific circumstance
- be made freely without pressure from anyone else.

If the treatment being refused is potentially life-prolonging, the ADRT must:

- be in writing
- be signed by you and witnessed
- say clearly that you want to refuse that treatment even if you might die as a result.

It's important when you're considering making an ADRT that you have all the information about why you might be offered a specific treatment, what the benefits and downsides are, whether there are any alternatives and the possible consequences of refusing it. Because of this, an ADRT is usually discussed with a senior member of your health team such as your GP, consultant or an advanced nurse practitioner.

The following are examples of some of the medical interventions that some people choose to include in an ADRT:

- a percutaneous endoscopic gastrostomy (PEG) – where a feeding tube is placed directly into the stomach for nutrition, fluids and/or medications to be given
- receiving a blood transfusion or blood products
- assisted ventilation – which takes over breathing if you're not able to breathe on your own
- cardiopulmonary resuscitation (CPR) – if your breathing or heart has stopped.

When you're thinking about what you might want to include in your plan, it's helpful to create clear and unambiguous instructions for different scenarios. It can be useful to think about treatments in bundles, such as what you would like to happen in the event of an infection. For example, if you're happy to receive antibiotics in some circumstances but not others, you would need to make this clear:

"I would be happy to receive antibiotics for a UTI or minor infection, but not if I develop sepsis."

Or you might decide:

"If I have trouble with my breathing, I am prepared to receive non-invasive ventilation, but I do not want mechanical ventilation if it is needed."

Non-invasive ventilation (NIV) is where a machine provides extra air through a mask or mouthpiece to assist your breathing. Mechanical ventilation is where a machine supports your breathing using a tube inserted through your neck into the windpipe.

Your ADRT must be followed, as long as it's valid and applies to your current situation. Remember, you can add to, or change, your plan at any time if there are additional situations you want to cover or your wishes change. This includes any ADRTs you have in place whilst you have capacity.

If you have an ADRT in place and then appoint someone as your LPA, you'll need to add specific instructions for your attorney(s) in your ADRT, otherwise it won't be valid. If the ADRT is written after appointing an LPA, it will take precedence.

7. What is a DNACPR decision?

If your heart stops beating and you stop breathing, this is known as cardiopulmonary arrest. Cardiopulmonary resuscitation (CPR) is the emergency procedure used to try and restart your heart and breathing. It might include chest compressions, rescue breaths and defibrillation (electric shocks).

Some people feel very strongly that they don't want attempts made to resuscitate them. Like other medical treatments, you can refuse CPR. This is done by completing a Do Not Attempt Cardiopulmonary Resuscitation (DNACPR) decision form. The health professionals involved in your care can tell you how to arrange this. It's important to remember that a DNACPR decision is only about emergency treatment when the heart stops, all other appropriate treatment would still be offered.

In some circumstances CPR is unlikely to work and could potentially get in the way of a peaceful and dignified death. If this is the case, the clinical team in charge of your care may decide not to attempt resuscitation. Neither you, nor your family, can insist that CPR be tried. However, wherever possible the clinical team should always discuss any decisions about resuscitation with you, or someone who is close to you to find out what your wishes would be. A DNACPR shouldn't be placed on your medical record without your knowledge. If you're unhappy about a DNACPR decision, you can discuss it with the clinical team involved or ask for a second opinion.

A DNACPR might only be for a short period of time and can be suspended or cancelled if circumstances change. For example, if your health improves; or if you need surgery, as CPR may be appropriate in the unlikely event that your heart or breathing stop during that short time.

If you have a DNACPR, it will be respected in most instances. However, it's not legally binding.

In England and Wales, you can include a DNACPR request in your ADRT. This makes it legally binding if the ADRT is valid. If you do choose to include a DNACPR decision, it's important to be clear about the circumstances in which you want this to apply. You might want to give the clinical team some flexibility, in case of unexpected circumstances, such as an accident.

8. Recording and communicating your wishes

The next step is to write down your wishes and preferences in a written statement. This is known as an advance statement. There are several different ways that you can structure and communicate your plans.

An advance statement doesn't have to be in any specific format, you can even write it on a blank piece of paper or in a letter if that's what you're comfortable with. However, a lot of people find it helpful to have a template to work with. It's also important to remember that if you wish to include an ADRT as part of your advance care plan this does have to be written and signed in the correct way to ensure it is legally binding in England and Wales.

You might find that your MS team has a particular template that they use. Some NHS Trusts and GP surgeries have forms you can use on their websites. The Preferred Priorities for Care is an advance statement template that is widely used and recognised by health professionals. It asks three basic questions:

"What has been happening to you in relation to your health?"

"What are your preferences and priorities for your future care?"

"Where would you like to be cared for?"

Your healthcare team should be able to provide you with a copy if they use this template.

If they don't, the MS Trust has devised a template to accompany this book that you might like to use (see further information).

An advance statement belongs to you and should be kept by you. This means you can update it or change it at any time. It can be helpful to keep a copy with you, even if you go out. At the very least, make sure your next of kin or someone close to you knows where your copy is so it can be easily found if needed.

Your family and the people providing your care can only act on your wishes if they know what they are, so it's important to share with them that you have an advance care plan and any ADRTs it contains. You might choose to simply let family know you have a plan and where they can find it. This might be a physical copy at home, or a digital copy saved on your phone or computer under the health or emergency sections. You may prefer to give them their own copy.

As well as letting any health professionals involved with your care know that you have a plan in place, it might be worth exploring if it's possible to have a copy of your plan kept with your notes. If this is possible, it's worth asking what would happen if you made changes to your plan to ensure any previous copies are replaced with the updated version. This way you can be reassured that they're aware of, and follow, your current wishes.

ReSPECT form

Some areas now use the ReSPECT (Recommended Summary Plan for Emergency Care and Treatment) form. This was developed by the Resuscitation Council and needs to be completed in partnership with a health professional involved in your care. The ReSPECT form is designed to give a brief overview of your wishes and has space to record if you have an advance care plan or advance decision to refuse treatment, and where these can be found.

There is also space to record whether cardiopulmonary resuscitation (CPR) attempts should be made or not. You can find out more about ReSPECT forms in further information.

Message in a bottle

In an emergency, you may be visited by paramedics or health professionals who don't have access to your medical records. The Lions Club International has created the 'Message in a Bottle' scheme so that any essential medical information can be accessed quickly in such a situation. It consists of a small bottle to put in your fridge which contains a form where you can record important medical information such as any allergies or medication that you take regularly. You can also record that you have an ACP and where it can be found.

You also receive two stickers; one for the inside of your front door to alert the emergency services to look for the bottle and one for your fridge so it can be easily found. Some GP surgeries and pharmacies stock the bottles or they can be obtained from your local Lions Club (see further information).

Summary Care Record

You may also have a Summary Care Record (SCR), this is an electronic record created from your GP medical records which can be accessed by authorised health professionals directly involved with your care. This can be helpful in an emergency. As a minimum it contains your name, address, date of birth and NHS number, any current medication and details of any allergies or bad reactions you've had to medication in the past. You can also include additional information to do with long term conditions, your care preferences and any additional communication needs. You can opt out of the system, so if you're not sure whether you have an SCR in place you could ask your GP.

9. Will my wishes be followed?

Advance decisions to refuse treatment are legally binding in England and Wales and must be followed if they are valid. Advance directives are not legally binding in Scotland. However, if a medical decision was ever challenged in the courts, provided the advance directive was valid and applied to the situation, it's likely a judge would rule to respect it.

Although advance statements and advance care plans aren't legally binding, if you have them in place, it does make it more likely that your wishes will be followed. If you can't make a decision for yourself, the team looking after you have to make a decision about what is in your 'best interests'.

There is a process to determining 'best interests' that must be followed. Part of this process is considering whether you have any known wishes or preferences that apply in the circumstances. If you have an advance statement or care plan, then this is a clear record of what your wishes are. So, unless it wasn't possible for some reason, your wishes will be respected.

Sometimes it might not be possible for your wishes to be met. This would include things such as:

- you've requested a family member/friend provides you with care they're unwilling/unable to give

“Thinking ahead can be an overwhelming process. It can lead to some powerful emotions, including sadness and grief, around the choices you’re making. It’s not unusual for you, or your health professionals, to be wary about starting these conversations.”

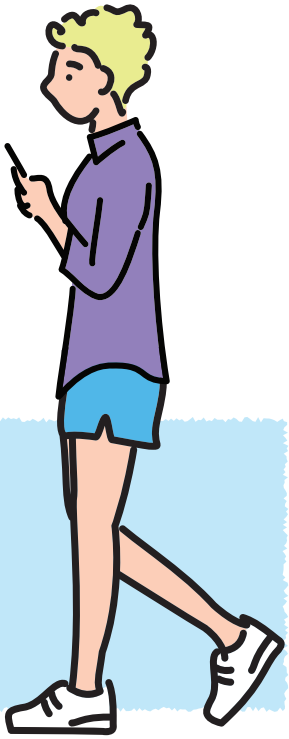
- unforeseen circumstances – for example, you might have documented that you don’t want to go into hospital but then have an accident that causes an injury that can only be managed in hospital, such as breaking a bone during a fall
- the care or treatment you’ve requested is clinically inappropriate.

Thinking ahead can be an overwhelming process. It can lead to some powerful emotions, including sadness and grief, around the choices you’re making. It’s not unusual for you, or your health professionals, to be wary about starting these conversations. However, it’s helpful to think about the choices you have whilst you have capacity. MS symptoms such as fatigue, thinking or reasoning difficulties and communication issues can potentially impact on your ability to plan and register your wishes.

It’s especially important to talk through your wishes and to share your plans with your family and those involved with your care. Not only can this give you a sense of control, but it’s also a way of determining whether your wishes are realistic. This gives you a chance to explore other options if they’re not. Remember, you’ll still be given the best possible care, support, and appropriate medication to control symptoms even if you choose to refuse a particular treatment.

Although it’s a challenging thing to do, many people find that planning ahead brings with it peace of mind. You know that your loved ones and health professionals are aware of your wishes and will do their utmost to follow them should the need arise. Once you’ve made your plans you can get on with living your life to the fullest.

Scan here for further information about advance planning and legal considerations.



About the authors

MS Trust Information Team

MS Trust brings together expertise from every angle to help everyone feel more in control of their MS today and every day.

Through trusted information and compassionate support, the training of new MS healthcare professionals, and research rooted in real experience – we're here for every MS, every day.

Ellie Garlick, MS Specialist Nurse, Queen's Nurse, Cambridge University Hospitals NHS Foundation Trust
Ellie developed her passion for ensuring that people live as well as they can until the end of their lives whilst working in district nursing in 2008. She followed this passion when she moved into hospice care offering education and training. In 2016, Ellie became an MS specialist nurse working within a multidisciplinary team offering patient centred care to people living with MS in Huntingdonshire. She currently works as part of the MS team at Addenbrooke's Hospital, seeing patients both in clinics and the community.

Sarah Roderick, Interim Head of Research and Engagement, MS Trust | Queen's Nurse
Sarah began her nursing career in palliative care in 1992, building a strong foundation in supporting people with complex and life-limiting conditions. She moved into district nursing in 2003, developing her expertise in community-based care. She spent 12 years as a Community MS Specialist Nurse, providing holistic, person-centred support to people with multiple sclerosis. Sarah has extensive experience across the full MS pathway, from diagnosis to advanced stages, helping people maintain quality of life and manage symptoms effectively. She has particular expertise in supporting individuals with complex needs within their community and retired from the NHS in December 2025.

Thank you

MS Trust Information Team

The MS Trust would like to thank all the people living with MS who have made this book possible by reviewing the text, especially Caroline, Chris and Ian. We would also like to thank the following health professionals for reviewing the text:

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Please contact the MS Trust information team if you would like any further information about the reference sources used in the production of the publication.

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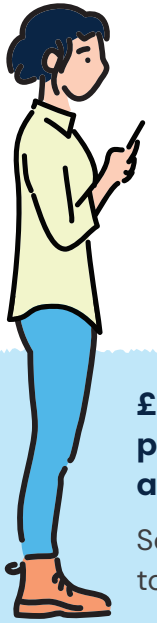
Thinking ahead: setting out your wishes for your future care and treatment



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