



More than 130,000 people in the UK live with multiple sclerosis. Despite that number however, the road to accurate diagnosis can be difficult. Some GPs lack the clinical expertise to spot the signs of MS so it can often be complex and tedious to get the required help.

In fact, new research conducted by talkhealth within the MS community has found that less than 30% of people with relapsing MS - the most common form of the condition - believe the NHS is easy to navigate. The system can be overwhelming and delayed referrals and limited follow-up care are a reality.

But there are ways to ensure that you receive the help you need sooner.

Managing multidisciplinary care



There's something of a postcode lottery when it comes to the level of care people living with MS receive in the UK.



Some areas are serviced by MS specialist centres in big hospitals which cater for a wide region while other places have community-based services led by MS nurses, neurologists, GPs, physios, speech and language therapists, counsellors and more.



In other words, you could see any number of healthcare professionals during your life post-diagnosis. If that does happen, make sure that you're keeping a record of who you see, when you see them and what actions they've recommended / you've taken:



- Keep a record of the names, locations, phone numbers, and email address of your various healthcare professionals.
- Record date of appointment with brief notes of what's been discussed and decided.



- Make copies of letters.
- Keep a symptom diary (the App store has wide range of options).

Expediting appointments

Ideally, we'd all like to be able to see a health care professional whenever we want - but the NHS is overstretched as it is.

According to the government's [NICE guidelines](#), you should have a comprehensive review of your condition at least once a year with your local MS service to check on how things are going. If you are on certain medications or depending on how active your MS is, you might need to be seen more often than this.

But what if you need to see someone more urgently?



- Make sure that you have your neurologist's NHS secretary's number. Calling them directly makes it a lot easier to get an emergency appointment.



- Your MS nurse, if you have one, is also a good contact as they can also send notes to neurologists and are able to ascertain whether it's actually a neurologist that you need to see or whether you need to see someone else.

How to get the most out of appointments

- 1 Write a list of questions you want to ask your MS nurse or neurologist - there's no such thing as a 'silly' question.
- 2 Put them in order of importance and ask the most important questions first. Sometimes it might be possible to email the questions to your MS team beforehand so they already know what to expect.
- 3 Take a friend, partner or family member along with you who can take notes or help remind you of certain points.
- 4 Keep a diary of symptoms and take it with you. If you're only seeing someone every few months, it can be hard to remember all the things that crop up.
- 5 Always ask for clarification if you don't understand certain words your GP/neurologist is using.
- 6 Ask for a second opinion if you're not happy with the advice you're getting. You can do this by asking your GP to be referred to another consultant.

Getting care from the NHS

Local councils tend to sort out social care and support but in some situations, the NHS will provide those instead - free of charge. It's not means-tested, meaning that anyone can access help. **The NHS** will provide up to six weeks of care after leaving hospital and continuous care if you have complex and serious health conditions.

Remember:

The NHS is here to help you but if you aren't receiving the support that you need, there are plenty of other avenues that can be explored which we'll be exploring in the next topics.

MS Nurses



Your MS team will be made up of umpteen different healthcare providers and may include an MS nurse. They are there to provide everyday support when you need it, to fast track appointments with your consultant and to do your health check-ups. [Check out the MS Society's video on how MS nurse Karen is transforming lives.](#)



next topic: *Patient support services*

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