

QuDoS in MS Recognition Programme Judges' Special Award Winner

Your name, job title, and centre:

Sarah Roderick, Queen's Nurse and MS Specialist Nurse,
Cambridgeshire and Peterborough NHS Foundation Trust

Ellie Garlick, Queen's Nurse and MS Specialist Nurse,
Cambridgeshire and Peterborough NHS Foundation Trust

Project / initiative name:

Huntingdonshire Community Multiple Sclerosis Specialist Nursing Team



Huntingdonshire Community Multiple Sclerosis Specialist Nursing Team being presented their award by Christine Singleton (right), Consultant Physiotherapist (FES), West Midlands Rehabilitation Centre (chair of judging panel)

Challenge

- There is a growing awareness in MS healthcare of the importance of advanced care planning, but many clinicians do not feel confident supporting their patients to think ahead.
- In our area, there were lots of people living with MS who weren't managing and were struggling a lot with their condition. We were almost just putting out fires here, there, and everywhere, with lots of people and families in crisis.
- We recognised a need for a resource for people with MS to provide information on advance care planning.

Solution

For patients who are newly diagnosed, we felt that those patients, those people needed more support than somebody who hopefully had been living with MS for a while and was maintaining their condition or having a good quality of life and managing their symptoms. We split our caseload up into different categories, and that then gave us almost a basis for how to support our patients.

We see people who have complex needs or whose condition might be progressing and are in a difficult phase of their condition more often, as well as those patients who might be coming to the end of their life or in the palliative phase.

Our main goal is to help people live as well as they can with their MS, but also to be as independent as they can, so that they can manage their MS independently and live as well as they can.

We've worked really hard to develop really strong links with the multidisciplinary team (MDT). Our team is part of the community neuro rehab team locally. We have good relationships with our neuro-occupational therapists, neuro physios, speech and language therapists, and the bladder and bowel service locally, so that we have that local knowledge to refer to and signpost people onto other services. They also get feedback from those teams, so that we can oversee and coordinate things for the care of people with MS in our area.

Plus, we do a lot of education of our patients, so that we're hopefully helping them develop the skills to self-manage their MS and then, hopefully, not need us quite so much or quite so frequently, but always being there as their support in the background to call on when they need to.

We also approached the MS Trust with an offer to collaborate on creating an information booklet for patients. The result was "Thinking Ahead – setting out your wishes for your future care and treatment", published in March 2022..

Results

A large percentage of our patients see us as collaborators. We're there alongside them and their families. Through education, we teach them when they need to contact us and when they don't need to, and how they manage their symptoms before they need to contact us. We teach them red flags and things like that, which then helps them to be in control, really.

I think we've also empowered our patients. There are a number of support groups that have been set up throughout the region, so they're able to support each other, as well as call on us to support them.

The other part of the feedback that we have had is the work with the MDT. If a patient needs an intervention from, for example, a speech and language therapist, we often do joint visits with them, which means then that they'll do their piece of therapy. Then, we join them when they're almost at the end of that, so that they can hand it back over to us, and we, the patient, and the family, know what the plan is going forward.

“It's been very satisfying for us when we meet someone, and they're in crisis, and we can do some really intensive work with them and really be led by their needs.”

Ellie Garlick
Queen's Nurse and MS Specialist Nurse,
Cambridgeshire and Peterborough NHS Foundation Trust

Next steps

We want to see if we can replicate our work further across the county and work with the teams that already cover Cambridge and Peterborough, and expand and collaborate more.

We've got big ambitions, having seen the difference we've made to the people we've had contact with. We've recently discovered that the number of people living with MS in the area that we do cover doesn't match up with our caseload, so we need to try and go and be more proactive in identifying people who should have access to us that don't at the moment.

What has been the biggest challenge?

One of the main challenges was identifying those people who've been living with MS for many years and aren't known to MS services.

We run clinics locally within all the different areas, so people can easily see us. We also offer home visits, and since COVID, we do a lot of video calls, phone calls, and emails.

We were both new to that whole area, and we had to find all the other members of the multidisciplinary team, build relationships with them, and find out how we could work together. Also, finding, linking with GP surgeries, and working out how they work was a challenge. I think that COVID has helped with communication for us, our patients, and other professionals.

How did you overcome this challenge?

We work in quite a rural area. It covers a large geographical area, so having the ability to do a joint visit with a speech and language therapist and a dietitian, online with the patient and the family member who might be in a different area, has also helped us.

What would be your advice to others wanting to replicate this project?

When you move into an area where there's an unmet need for people living with MS, it can be quite overwhelming because there are just people coming from all angles, asking for help and support. The way we initially started was just putting things down on paper, writing a plan, and prioritising what needed to be done first.

Getting to know the other members of your team is also really important. We collaborate with professionals, but also family members and our patients, and see ourselves as a team, as a whole, as opposed to patients and professionals. We see ourselves as working together.

Take a break.

Make a cup of something and enjoy an interview with, Ellie Garlick and Sarah Roderick for winning the Judges' Special Award.



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