

QuDoS Multiple sclerosis: NHS case studies 2019

Outstanding MS occupational therapist

Your name, job title and centre

Susan Hourihan, Lead Occupational Therapist (Neuro-Sciences), National Hospital for Neurology and Neurosurgery

Project / initiative name

MDT transition clinics

Project start date

2008



Challenge

During my MSc in MS practice, I found that there was a group of patients who were transitioning between relapsing and progressive disease. These patients, who are hard to identify as there is no diagnostic criteria for transition, face a number of challenges:

1. Transition to progressive disease can be a challenging time psychologically. Some people find the diagnosis of progressive disease as difficult, or sometimes more difficult to adjust to than the original diagnosis of MS.
 2. Transition to progressive disease may impact on a person's eligibility for disease modifying drugs.
 3. Transition to progressive disease signals the accumulation of disability. This presents a number of practical challenges, such as applying for benefits or leaving/staying in work.
 4. Progressive disease can lead to or enhance a number of disabling symptoms, such as spasticity and bladder issues.
- We felt standard neurology follow-up appointments did not have the capacity or the resources needed to help people overcome these challenges.

Solution

1. Susan Hourihan, lead neuro-sciences occupational therapist, worked with neurologist Dr Jeremy Chataway and Bernadette Porter, Consultant MS Nurse to start an MDT transition clinic.
2. General neurologists and GPs refer patients they feel are transitioning to progressive disease into the team for a one-hour session.
3. The patient's medical history is first assessed for signs of transition to progressive disease.
4. If the team agree with the referring clinician's conclusion, the patient's needs are holistically assessed.
5. They are given general information on the progressive stage of MS and are referred into other services that may be relevant to them and their needs. That might be psychology, FES, upper limb electrical stimulation or splinting, fatigue management, vocational rehabilitation or bladder intervention.
6. The team have also upskilled themselves on issues surrounding benefits and housing in order to offer advice and signpost patients to appropriate outside services.

Results

We regularly collect feedback from our patients. They frequently tell us that before they attended the transition MDT, they thought they had "reached the end of the line" in terms of intervention options. They tell us that they feel reassured and supported, and that the sessions helped them to see they had a future.

Next steps

We are now looking into offering people one MDT annual review clinic slot a year.

Many people have told us that their needs frequently change in the years after transiting to progressive disease. Annual reviews would allow us to make sure they are connected to all and any help that is available.

What was the biggest challenge?

The biggest challenge was the logistics of lining up everybody's diaries and finding available rooms.

How did you overcome the challenge?

All the staff involved in the project understood the value of offering this support and were keen to make it work.

We also built strong links with the staff responsible for booking rooms in the hospital. We explained what we were trying to achieve and over the course of two sit-down meetings were able to find a room that was available at the right time and was big enough to accommodate all the members of the team.

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

1. Make sure this is a service that your patient group would benefit from.
2. If you do not have a huge caseload, you might not need a separate transition clinic. Transition clinics can be carried out in a regular MDT clinic, but make sure you have the right skills in the room.
3. Be aware of what services people in this phase of the disease are likely to need: psychology, help with parenting, help with staying in work, fatigue management, help with managing bowel and bladder problems, help maintaining mobility and keeping active, orthotics, electrical stimulation and symptom management.
4. Make links with the services you are likely to refer into.
5. Understand which areas you may need to upskill in.
6. Be aware that the clinic is just a part of the process – it can take just as much time to make and follow-up on the referrals.

Testimonial quote



From a patient

Once I found out that I was going to be supported in the transition clinic, I suddenly felt so much better and I was going to be taken care of. I don't know how I would have coped without it."

Gold Sponsor



Silver Sponsors

