

QuDoS Multiple sclerosis: NHS case studies 2019

Outstanding specialist nurse commendation

Your name, job title and centre

Katie Hanson, Clinical Nurse Specialist for MS and Neurology for Paediatrics, Great Ormond Street Children's Hospital

Project / initiative name

Various projects, such as the establishment of a working group for paediatric MS team nurses and 'family days' for patients and their wider support network

Project start date

Projects running through 2019 to 2020



Challenge

- There is a lack of funding across the board for care services, which means that there is also a lack of resources
- An unmet need exists for tailored transition documents and advice for teenagers with MS in the region, specifically tailored to 'transition' (ie, the gap between MS care for children and adult services)
- There was a lack of communication and sharing of best practice between paediatric MS nurses from across different services, which meant little opportunity for learning from peers.

Solution

- A working group for paediatric MS nurses was established (currently a small group comprised of six members); the group get together regularly to share ideas and are creating an MS transition document for teenagers that is tailored to individuals in the service region
- The working group also meet up at various MS conferences thereby creating opportunities for peer learning experiences (ie, sharing of best practice between paediatrics-focussed MS nurses)
- These learning opportunities have led the working group to begin development of a new standards document for blood monitoring, specifically in children and teenagers with MS.

Solution cont...

- 'Family days' have been initiated, which are educational informative days for families of those with MS (eg, parents), with Q&A sessions and opportunity for discussion between the care team and the patient's wider support network.

Results

- Families have been keen, pro-active and appreciative of the family days
- The transition support provided fills a key unmet need by identifying and stopping patients from 'slipping through the system' when they move from paediatric to adult services
- The working group has allowed sharing of best practice between peers, improved communication across services and created learning opportunities for all those involved.

Next steps

More family days are planned for 2020: one in April and another two (covering separate neurological conditions) later in the year. The networking with other paediatric MS nurses will continue and transition documents will be finalised for roll-out later in 2020. Feedback will also be collected and incorporated.

What has been the biggest challenge?

It is challenging to be an MS nurse specialist in a region without a larger support team, especially when covering other neurological conditions too; plus, getting bloodwork can sometimes be challenging.

How did you overcome this challenge?

The MS Trust study day was helpful in terms of covering what to do with different bloodwork results; delegation across the available team to share care responsibilities has been crucial, plus teamwork and collaboration help. Speaking with other teams and developing 'how-to' documents has also been valuable.

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

- Organisation and time management is important – time must be set aside for new initiatives and sharing of best practice. Getting a 'buddy' or support from other teams and specialist nurses from other services can help
- If considering initiating 'Family days' be sure to get parents' and families' insights and/or feedback on what they want from the day; family days should be tailored to what the unmet needs are for your particular service / region
- Collaborate – make it a team effort; the MS paediatric nurse working group has been valuable for insights sharing and support for new ideas

Testimonial quote



From a colleague

Katie helps prepare older teenagers to transition to adult services or go off to university. She is a nurse, but she also counsels them, treating each patient as an individual... She is [also] in the process of setting up a workgroup for MS nurses and teams from around the country. She has organised events during which all the members discuss treatments and new research. They also discuss how they work and talk about the systems in their centres in terms of diagnosis and treatment, particularly in paediatric MS. The idea is to share best practice and improve care by learning from each other."

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