Resource

The Clinical Nurse Specialist

A Clinical Nurse Specialist in paediatric rheumatology is a trained children’s nurse who has specialist experience and has undertaken further training to be able to look after your child’s physical, emotional and social needs.

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A Paediatric Rheumatology Nurse Specialist (PRNS) is a trained children’s nurse who has specialist experience and has undertaken further training to be able to look after your child’s physical, emotional and social needs. They are also known as Paediatric Rheumatology Clinical Nurse Specialists (CNS), Paediatric Rheumatology Nurse Practitioners or simply as Specialist Nurses. The PRNS is a key member of the multi-disciplinary team whether it’s in a specialist paediatric unit or community based hospital.

The PRNS can help your child and family to learn about the diagnosis, the treatments and therapies offered, managing medications, understanding test results and helping you and your child cope with the emotional impact of a potentially long term condition. They are also a good source of knowledge if your child needs support and advice in managing their symptoms and treatment or, if you have any concerns about your child and can also liaise with other healthcare teams, schools, social services and voluntary groups and agencies on your child's behalf. They can also help when things don't go exactly as planned. By listening to you and your experiences they can help improve things for you and your child in the future.

When you and your child come to clinic you'll see the consultant and the PRNS; some PRNSs alsorun their own nurse-led clinics to see and assess children and ensure that treatments are working effectively in the same way that a doctor does. This means they provide a 'one-stop' clinic and can:

- take blood samples if needed and interpret the results.
- give steroid joint injections as well as administering other treatments and therapies.
- organise X-rays for your child to have done at the hospital after you've seen the consultant and before you go home.
- refer your child to the physiotherapists or occupational therapists for help with exercises, or independence in their normal daily activities.
- refer to a podiatrist who can assess your child's gait and provide corrective/supportive insoles.
- organise for you to collect any medicines your child needs to take home with you following your child's appointment.
- liaise with ophthalmology (eye specialists) if your child has additional difficulties in this area.
- Help you to manage some of the daily challenged and problems you and your child may experience.

The PRNS isn't just concerned about your child's physical wellbeing but also their mental and emotional health and their links to the local Children & Adolescent Mental Health Service (CAMHS) or team psychologist means they can ask them to see your child if they need extra help and support to adjust to living with a long term condition.

The PRNS also plays a key role in helping you and your child navigate the process of moving from paediatric to adult rheumatology services, known as the transition. Children and young people are usually seen in clinic together with their parents but sometimes you or your child, especially if they are coming up to or are already a teenager, may want to speak to the PRNS on their own. This can be arranged and a separate room or area made available away from the clinic room where they can talk to your child, or indeed you if you also have any worries or concerns, about anything from general arthritis management, medications and other treatment options including how to give injections, offer support following diagnosis and anything which may be worrying either of you.

All PRNSs, whether based in a specialist centre, a district general hospital or in a community based hospital have good access to the necessary services and work hard to provide a good service geared towards giving your child the physical and psychological means to manage their condition effectively and to lead a full, active and fun life with their support and encouragement.

Although there aren't many PRNSs in the UK they are a very friendly bunch who often communicate with each other as well as their colleagues across the world to share problems, good ways of working and, as most PRNSs are involved in national research projects, their knowledge and experience of new research.

Often families can contact their PRNS directly via an advice line, direct phone number, department email or hospital pager system. This helps you to make contact easily with someone who knows about your child, you, your child’s condition and the treatment plans. Your PRNS will never mind being asked any questions, will like sharing good advice and tips from families and love helping your child to remain happy, active and able to achieve their potential.

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