

Contact numbers

Clinical nurse specialist for rare neurological illness

Tel: **0118 322 8707**

Monday – Friday 8.30am – 4.30pm
(answerphone available), or email

jane.owen@royalberkshire.nhs.uk

caroline.crowley@royalberkshire.nhs.uk

Unfortunately, there is no emergency service. If you need urgent assistance, please contact your GP, out of hours' service or NHS 111.

If you are admitted to hospital at any time, please ask staff to inform your clinical nurse specialist.

My clinical nurse specialist is:

My key worker is:

Other useful numbers

Royal Berkshire Hospital
Main Switchboard: 0118 322 5111

Huntington's Disease Association
0151 331 5444

Myasthenia Gravis Association
0800 919922

Ataxia UK Helpline
0845 644 0606

British Polio Fellowship
0800 018 0586

To find out more about our Trust visit
www.royalberkshire.nhs.uk

Please ask if you need this information in another language or format.

RBFT Neuro-Rehabilitation, June 2023

Next review due: June 2025



Royal Berkshire
NHS Foundation Trust

Clinical nurse specialist for rare neurological illness

Information for patients, relatives and carers

This leaflet aims to answer some of the questions you may have about the role of the clinical nurse specialist for rare neurological illness.

What does the clinical nurse specialist (CNS) do?

He / she is able to offer clinical expertise, support and information for patients with complex progressive neurological conditions.

This includes patients who have:

- Huntington's Disease
- Myasthenia Gravis
- Post polio syndrome / Late onset polio
- Ataxia

There are other progressive neurological conditions that are not included above. Please call to discuss whether this service applies to your condition.

The clinical nurse specialist will review you in between reviews by your neurology consultant. These reviews can be done in clinic, via video or telephone consultation, or if required, he/she can visit you at home. The nurse specialist also has joint clinics with the consultants.

Your multidisciplinary team

There are many health professionals and services that may be involved in your care to help maximise your independence, dignity and quality of life.

These include: community nurses, dietitians, occupational therapists, physiotherapists, palliative care, respiratory services, social services and speech and language therapists.

The CNS works closely with these services and will take the lead to coordinate your care.

What can the clinical nurse specialist offer you?

- Information about your illness.
- Advice and support for you, your relatives, carers and friends.
- Advice on your continued care at home.
- Help with physical symptoms, such as saliva management, breathlessness, cramps, fatigue or nausea.
- Refer you to other services that may be able to help you, such as occupational therapy, physiotherapy, speech and language therapy, wheelchair clinic and more.
- Advice and support when making decisions about specific interventions.
- Signposting to services that can help to apply for benefits.
- Liaison with charitable organisations, especially those pertinent to your illness.