

Specialist Ataxia Nurse Service South West

Your multidisciplinary team



ATAXIA
Ataxia UK

This leaflet aims to answer some of the questions you may have about the role of the Specialist Ataxia Nurse for the South West.

What can the Specialist Ataxia Nurse do for you?

The Specialist Ataxia Nurse can:

- Provide information and support about ataxia for you, your family, carers and friends.
- Advise on recognition and management of symptoms like mobility, speech, swallowing, bladder and bowel changes, sleep, sexual function and diet.
- Provide emotional and psychological support.
- Offer one-to-one consultations by phone or video.
- Assess your individual needs and care priorities.
- Advise and support you with decisions about treatments and interventions.
- Give guidance on ongoing care at home, future planning, and end-of-life care.
- Assist you in accessing local services and healthcare professionals.
- Provide advocacy and support when dealing with health and care services.
- Attend specialist clinic appointments with you (where appropriate).

The Specialist Ataxia Nurse cannot:

- Visit you at home.
- Take the place of your GP or neurologist.
- Provide an emergency service.
- Manage the treatment of your ataxia.

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

The Specialist Ataxia Nurse works closely with these services and will be able to assist you in accessing these services.

The Specialist Ataxia Nurse is not part of the NHS and cannot manage the treatment of someone with ataxia, but they can speak with the health professionals who do treat patients with ataxia.

It is important to continue accessing care from your local neurology team. Where possible, you may also benefit from referral to a specialist ataxia centre, where consultant neurologists with expertise in ataxia can provide additional support.

Who is the service for?

To be eligible for the Specialist Ataxia Nurse Service:

- You must live in the NHS-defined South West region of England.
- You or a family member has a confirmed diagnosis of a progressive ataxia, or a suspected diagnosis based on family history of ataxia.
- If you are unsure if you meet these criteria, or if you do yet have a diagnosis, please get in touch with us.



For a referral to the Specialist Ataxia Nurse Service South West:

Please fill out the referral form on our website:
<https://www.ataxia.org.uk/support-services/sw-specialist-nurse/>

or

if you are unable to complete the form, contact us via the Helpline (see contacts details overleaf).

If you need urgent advice, you should contact your GP or NHS 111.
In an emergency, please contact 999.

The Ataxia UK Helpline is here to help!

Ataxia UK wants to ensure everyone affected by ataxia has access to the information, advice and support they need to live their best life.

The Helpline is more than a place to find out about ataxias: it's a resource and support hub for people who are affected by ataxias, in all aspects of your life. As well as providing support and information around diagnosis, treatment and living with ataxia, there is a range of other issues we can help with, including:

- Benefits
- Housing
- Finances
- Care needs
- Health needs
- Mental health
- End of life care
- Transport and travel
- Employment
- Education
- Accessing Grants
- Aids and adaptations



<https://www.ataxia.org.uk/>

If you feel you are able to make a donation towards helping us continue this work, please follow the links below.

How to make a donation

If you would like to gift a donation to Ataxia UK, please use the QR code below:



Or go to the website
<https://www.ataxia.org.uk/donate-to-us/>

Helpline

If you would like to find out more, or talk to a member of the team, please get in touch.

Open Monday to Thursday
10:30am until 2:30pm

help@ataxia.org.uk

0800 995 6037