

If Ataxia Specialist Nurses are the answer..... What's the problem?

Workshop for Ataxia Annual Conference 2022
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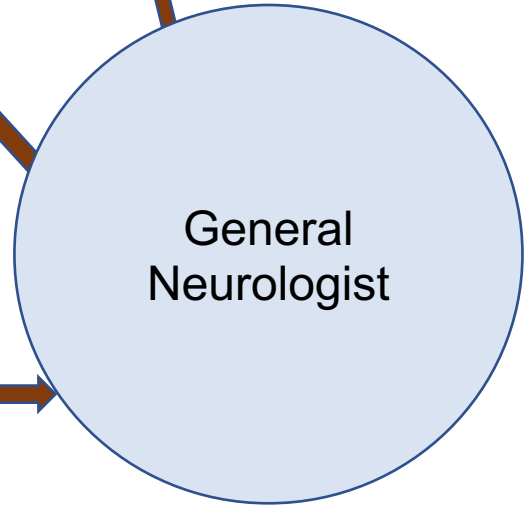
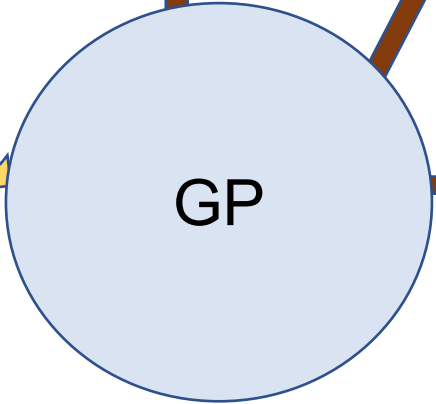
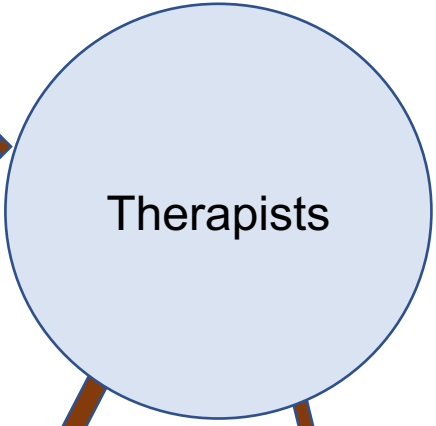
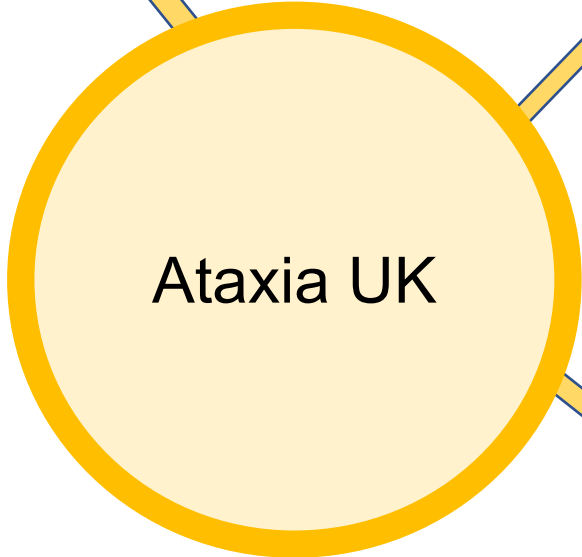
ATAXIA

If Ataxia Specialist Nurses are the answer.... What's the problem?



- **49%** 12+ months after GP visit to be seen by a neurologist (NNPE)
- **42%** additional 12 months to be diagnosed. (NNPE)
- **44%** lack of emotional support. (AUK2020)
- **43%** lack of information about ataxia and symptoms (AUK2021)
- **38%** lack of practical support (AUK2020)
- **28%** completely understood the explanation of their diagnosis given at diagnosis (NNPE)
- **74%** felt lack of knowledge from GPs and other primary care professionals. (AUK2021)
- **35%** felt lack of knowledge from consultants or neurologists (AUK2020)
- **68%** not asked about mental wellbeing by a health or social care professional (NNPE).
- **28%** had access to speech therapy which met most needs. (AUK2020)

Website Internet Search
Word of mouth Press
Social Media



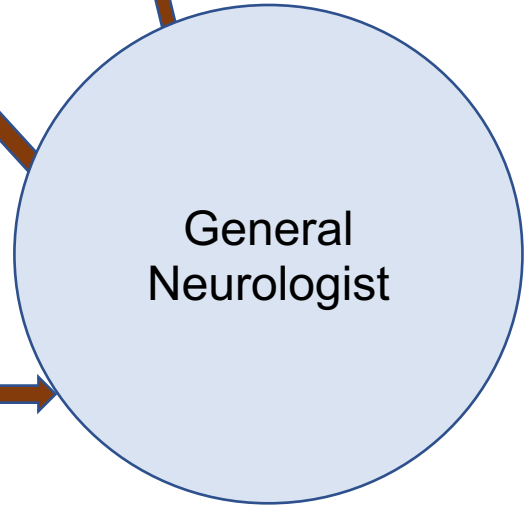
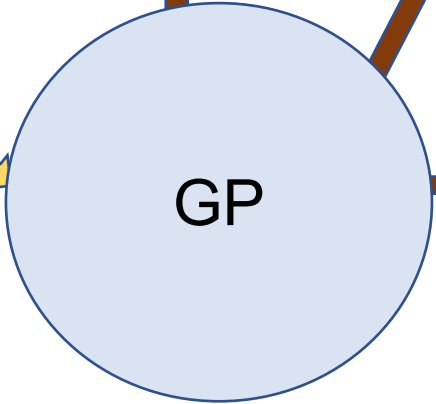
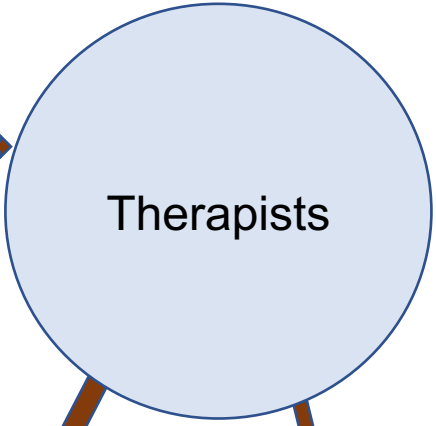
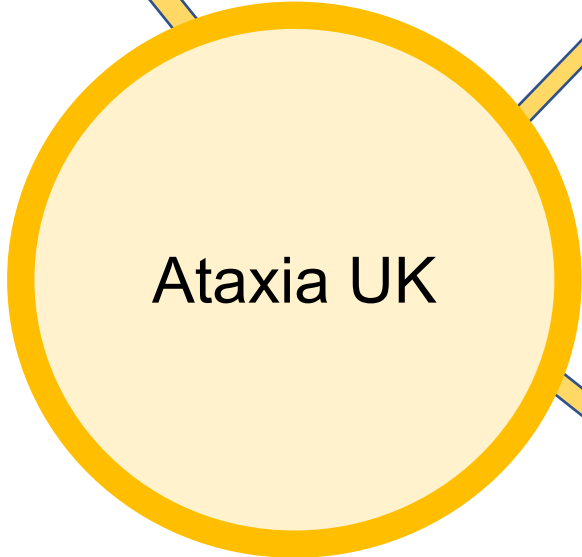
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What can Specialist Nurses Bring?

- Knowledge of, and insight into, the patient pathway/services available
- High-level expertise in the care of a specific patient group.
- Additional qualifications - meaning they can perform advanced tasks
- Considerable knowledge of the organisation in which they work, and of partner organisations

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Aim: To improve the quality of life of people affected by ataxia.

- Improve access to treatment and care
- Faster diagnosis
- Individual support
- Information, advice and support to enable informed decisions about the future; access entitlements; and exercise rights.
- Reduce mental health consequences of ataxia

Impact: people will be able to...

- Access appropriate care including therapies mitigating the physical impact of their condition.
- Increase their incomes/reducing the impact of income loss by claiming their benefit entitlements, and dealing with money and debt issues.
- Plan financially for the future.
- Deal with housing issues and make appropriate housing choices.
- Deal with employment issues, including around hours, retirement and reasonable adjustments.

Aim: To improve the quality of care the NHS can provide to people affected by ataxia.

- Information, advice and training to clinicians and therapists to raise their awareness, interest, and understanding of ataxia.
- Improved networking between clinicians and therapists, and ataxia expert clinicians and therapists – creating a Hub and Spoke Model
- Development of further ataxia clinics
- Swift adoption of proven treatments when available.

Views

“The biggest advantage of MS nurses is helping to deal with the uncertainty around MS. Their emotional support is invaluable. My GP is experienced and good but admits to having limited experience of MS.”

Person with MS

“MS nurses are invaluable. They take the pressure off consultant time. They enable patients to be seen quickly. There would be hell to pay if they were taken away.”

Consultant Neurologist

“The MS nurse specialist is a safe pair of hands. I can discharge from hospital to the nurse and she can refer back to me if there is a problem.”

Consultant Neurologist

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