



Diagnosis and Referral Project

In May 2007, Ataxia UK commissioned a study to explore the issues of referral and diagnosis with people with ataxia, and their carers, in three different regions in the UK.

Background

Ataxia UK had been made aware, from various sources, that diagnosis is often slow for people with ataxia. It was not known if there was a widespread problem of people being denied access to referrals to Ataxia centres or indeed to neurologists. Ataxia UK wanted to find out more about whether people are experiencing referral problems or not, and the nature of those problems. We also wanted to identify other problems that people may experience before reaching a diagnosis.

Methodology of the study

This study explored issues of referral and diagnosis with people with ataxia and this was done through discussions at focus group meetings. The discussions followed a topic guide that had been produced specifically for the study, based on the Guidelines on Best Clinical Practice¹. The focus groups were arranged via Ataxia UK and were held in locations where there are already support groups; Peterborough (Ataxia-East group), Uckfield (East Sussex and Kent group) and Edinburgh (East of Scotland Group). Notes of the discussions were written up and analysed.

Results of the study - Recommendations

Guidelines and pathways

- There is a need to define and communicate clear care pathways across primary, secondary and tertiary care, and bridging health and social care, to ensure that people with ataxia receive expert care and support from the point of diagnosis and throughout their experience of living with ataxia.
- These pathways should be communicated clearly to people with ataxia, and their carers, in order that they know what is available and what to ask for in terms of support and referrals.
- Ataxia UK guidelines which set out indications for the pathways should be widely distributed to practitioners in health and social care.

¹ Management of Ataxia: Guidelines on Best Clinical Practice, March 2007, Ataxia UK.

Awareness of GPs

- Work to increase GPs' awareness of ataxia should be developed, including for instance, the importance of taking a family history and asking about similar symptoms in other members of the family when a neurological condition or movement disorder is suspected.
- The value of having a diagnosis, from a patient's perspective, should be communicated and understood by GPs and other health professionals.

Diagnosis

- A diagnosis of ataxia should be given by a specialist neurologist or a fully informed GP, depending on the circumstances. The presence of a specialist nurse to support the patient and to help answer questions should be considered.
- Follow-up appointments should be routinely offered shortly after a diagnosis of ataxia. A period of a few weeks, rather than months, is thought to be an ideal time for initial follow up.

Specialist ataxia centres

- People with a diagnosis of ataxia should be offered a referral to an accredited specialist ataxia centre as a matter of routine.
- Further ataxia specialist centres should be developed in order to increase access and improve the geographical spread of the centres.

Information and advice

- People with ataxia should be offered information and advice without having to ask for it. Repeated offers of information may be appropriate as individual requirements vary throughout the course of an individual's experience of ataxia.
- People with ataxia should be made aware of the availability of genetic counselling for themselves and their families.
- All people with ataxia should be made aware of Ataxia UK and the support and information it can offer as soon as a diagnosis is made.
- Service providers should review how they give information on benefits, services and sources of support to people with ataxia, and should ensure that they can provide the necessary information or signpost people towards appropriate places where they can access the information they need.
- Clinicians should be prepared to spend time helping people to understand and evaluate information that they obtain from a variety of sources, e.g. leaflets, the Internet, media articles.

Needs of carers

- The needs of carers of people with ataxia should be considered, and carers should be offered their own assessment.

Access to specialist care

- People with ataxia should have access to specialist nurses. These may be specialists in neurological conditions or movement disorders.
- People with ataxia should have access to therapists with specialist experience of ataxia and/or other neurological conditions.

Awareness of other health professionals

- Hospital staff should be made aware of the implications of ataxia on other medical conditions, and vice versa.

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