

§ Recognise that you are a carer: Many carers do not consider themselves to be carers. You may be a husband, wife, child, parent or friend of a person diagnosed with ataxia. You are 'just' looking after your child, partner, mother, or friend - what anyone else would in the same situation. (And because many ataxias are inherited conditions, you may have ataxia yourself.)

The fact is that you are also a carer, and there are things that you need to know. Recognition of your role is the first step in getting a range of help and support.

- § Find out about ataxia and, where appropriate, the specific nature of the ataxia diagnosed from reliable sources such as the Ataxia UK website www.ataxia.org.uk
- § Seek support from people who are effective, compassionate and sensitive to your needs.
- § 'Common sense' is not always a complete guide to caring and coping. Training for relatives and friends in their new or changing role as carer has a place.
- § Join an appropriate self-help group. There are carers' organisations and Ataxia UK has a network of local groups and branches which offers support and friendship to everyone affected by ataxia, including carers. Carers' organisations and Ataxia UK also offer support via the Internet.
- § Make sure you heed the needs of all members of the family.
- § Constant unconditional self-sacrifice makes effective caring and coping impossible. Don't neglect existing friendships, and participate in activities that take you out of the house.
- § Just as the person with ataxia should be as independent as possible, now and as ataxia progresses, you too have a life independent of them.
- § The ability to change and adapt, to look at things differently, will help you to cope.
- § Take good care of yourself.

*Thanks to all those who contributed to this information sheet. **If you are a carer for someone with ataxia and would like to share your experiences, we would love to hear from you.***

For more support or information please contact:

Ataxia UK, Lincoln House, Kennington Park, 1-3 Brixton Road, London SW9 6DE

www.ataxia.org.uk

Helpline: 0845 644 0606 Tel: 020 7582 1444 Email: helpline@ataxia.org.uk

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