



Ataxia
UK

Caring today
Researching for tomorrow



ataxia
a parents' guide

contents

ataxia: a parents' guide	4-5	Sports	20-21
Words from parents	6-7	Walking aids	22-23
Medical information	8-9	Wheelchairs	24-25
Schools & education	10-11	driving	26-27
Higher education	12-13	Assistance dogs	28-29
Sibling care	14-15	Preparing for adult life	30-31
Out & about	16-17	Getting support	32-33
Leisure & holidays	18-19	Conferences	34-35



ataxia

a parents' guide

This booklet is aimed at parents and carers of children with ataxia.

Ataxia is the name given to a group of neurological disorders that affect balance, coordination, and speech.

There are many different types of ataxia that can affect people in different ways.

Sometimes ataxia can be transient and children get better after a few months.

However, this booklet focuses on the types of ataxia that do not improve, and in many cases are progressive.

Anyone of any age can start to display symptoms of ataxia, but certain types are more common in certain age groups.

For example, people with Friedreich's ataxia are usually diagnosed in childhood or adolescence.

Ataxia UK has produced a series of leaflets specific to different ataxias that can be requested from the Helpline or downloaded from our website.



words from parents

We asked parents of children with ataxia what they'd say to other parents, who'd just found out their child has ataxia.

This is their advice:

“ Take one day at a time, don't look too far ahead, everyone is different, progression happens slowly so your child will not change overnight.

“ Encourage them to ensure that your child remains as independent as possible. Get referral to neurology department. Push medical staff for what you feel is required.

“ Get support for yourself from wherever you can (as well as the child). Find someone who is good at listening that you can offload to if needed.

“ Don't look too far into the future. The ataxia may progress slower/quicker than the information given. Have a positive attitude and make the most of good health/days.

“ There are a lot of people worse off than your child – at least it doesn't affect their brain. Ataxia is a blow, but allows you to value things so much more. Your life will be different, but there is no reason why you shouldn't enjoy it. It does not mean it's the end of the world.

“ Ask for help from the relevant people, and do it now. Shout, scream, until you are listened to. Ask questions, and lots of them. Ask for time with the doctors without your child so you can ask questions that you feel uncomfortable asking with your child present. Give yourself a hug, give your child a hug, remember to be adaptable, things change, so enjoy every moment you can, smile.

Sheila's son was diagnosed with Friedreich's Ataxia (FA) at the age of 9 and is now 24

Alison's daughter was diagnosed with FA last year and is currently 11 years old

Pauline's daughter was diagnosed with cerebellar ataxia at the age of 2 and is now 6 years old

Tricia's son was diagnosed with FA last year and is currently 6 years old

Pippa's son has an undiagnosed form of ataxia. He is now 7 years old

medical information

For children, the diagnostic pathway normally involves a GP referring to paediatric services.

Between the ages of 16 and 18 they would be referred to an adult neurologist. It is recommended that people with ataxia are seen at least annually by a paediatric neurologist or adult neurologist to monitor the condition. There are clinicians who specialise in ataxia and it is possible to get referrals to them. Contact the Ataxia UK Helpline for more information.

There is variability in the symptoms experienced by children with ataxia, partly depending on the condition they have been diagnosed with. More information on symptoms can be seen in Ataxia UK's leaflet: **Ataxia - what's that?** Although there is no cure, there are treatments for some of the symptoms experienced.

If children develop problems with slurred speech or swallowing food, a speech and language therapist is very helpful. A referral to a physiotherapist is recommended to preserve mobility and to avoid other problems, such as ones associated with being in a wheelchair.

An assessment from an occupational therapist is important to ensure that the house is fully adapted for the child and to help the child in many other aspects of daily living (see later sections).

The emotional aspects of having a long-term neurological condition such as ataxia can have an impact on the child and family life, and help is available via counselling or other interventions on which the GP can advise.

To help medical professionals, who might not have much experience of this, Ataxia UK has collaborated with ataxia specialists and produced medical guidelines. These can be requested from the **Ataxia UK Helpline** or downloaded from the website and contain detailed information on diagnosis, patient pathways, medical interventions, therapies and research. Some parents find it beneficial to provide copies to healthcare professionals that care for their children such as their GP or paediatrician.



schools & education

Schools and local councils are forbidden from discriminating against pupils for reasons relating to a disability, and this includes ataxia.

Although the physical accessibility of schools varies, in general, modern facilities accommodate pupils with disabilities.

It is advisable to research individual schools in order to get specific information about their accessibility and any plans for improvements. This information can be found in a school's accessibility plan, a copy of which must be provided on request.

The local council and current school should both be helpful in advising on further education. If the local college cannot offer a course to suit your needs, **Skills Funding Agency** ([skillsfundingagency.bis.gov.uk](https://www.skillsfundingagency.bis.gov.uk) or 0845 377 5000) should consider funding a place at a more suitable college. Most of these colleges are independent and are specifically for students with disabilities or learning difficulties.

SKILL, the National Bureau for Students with Disabilities (www.skill.org.uk or 01535 645 453) is an organisation for young people who are over 16 and in education and looking for work.

“ Most primary schools cope well for children with ataxia, everything is small and achievable.

Secondary school is another matter, obviously you go with the flow, but a lot can be done to help. Most state schools are brilliant at special needs, but they don't always know what's needed.

A laptop is a must. People to carry your stuff for you is a help as it can get very heavy.

The key is to keep going – the children/parents mustn't use ataxia as an excuse not to be able to achieve academically as much as any ordinary child.

“ Having 6 children (3 with ataxia), I have decided that every child is different and that they all have different needs. The most important thing about schooling, I believe, is that the child is happy.



higher education

Going to university may be the first time your child has been away from home for an extended period of time.

We have an information leaflet on going on to higher education which can be requested from the Helpline, and a chapter on preparing for adult life (pages 30-31) may also prove useful. Below are a few tips to get you (and your young adult) started.

Top Tips

- If your child is a wheelchair user, check 'wheelchair accessible' doesn't just mean 'on the ground floor' - they may have problems in narrow corridors or small doorways.
- Check if accessible toilets on campus use the **RADAR** key. A RADAR key can be bought from the local council.
- Ask how many current students have disabilities. This gives you an idea of how well they cope with people with disabilities.
- Find out how to apply for **DSA (Disabled Student's Allowance)**, for funds towards equipment or personal helpers, for example.
- Ensure staff who will be working with your child are fully aware of ataxia, their needs and any special arrangements needed. You must state that they do want staff to be informed, otherwise they will not be told.
- Before applying to university, check that there is suitably accessible accommodation in halls or nearby.

Disabled Student's Allowance (DSA)

The DSA is a grant provided by central government through **Local Education Authorities (LEAs)** to assist students with an **ALN (Additional Learning Need)** to meet the additional costs they might incur whilst studying at university (like cost of specialist equipment, a note-taker and extra travel costs). The DSA is available to full-time and part-time undergraduate and postgraduate students, and distance learning students. Other sources of funding may be available depending on your circumstances. Ask your LEA, Registry or the **Students' Advice Centre**.

Application forms are available from the local council, or go to:
www.gov.uk/disabled-students-allowances-dsas

“ if you are clever there are grants for a lot of things, don't be afraid to ask.

My 19 yr old son is a real wheeler dealer. At the age of 16 he had his own car, (you can also legally drive at 16, but this is NOT a good idea - they are just too young) from Motability, this was the only way he was going to get his insurance paid.

He has a residential bursary as he attends Bristol college, so they pay 75% of his rent.

He also has a maintenance grant from the college to help him buy food (about £80 per month - not a huge amount but free.)

He gets his Disability allowance of about £50 per week as the other £50 goes towards his car. Between the ages of 19 and 24 Motability will also pay for 30-40 hours of driving lessons.

We have also found a local charity set up by a couple who died, funding equipment for disabled people within our area, we are going to apply for his tricycle through them.

My advice when going to any college is to ask what they have to offer. You get a free (car) tax disc if you have disability living allowance.

sibling care

A sibling or a person with ataxia can easily fall into the role of carer.

Knowing and caring for someone with ataxia allows children to develop key skills such as loyalty, understanding and patience, all of which are valuable throughout life. On the other hand, it is important to be aware of how a sibling can be affected, how they are feeling and offer help and advice on ways to cope. It may be the case of simply being there to listen when they need someone to talk to.

Every child and family is different. Here are a few general pieces of advice offered by parents:

- Give information about the child's condition to the sibling
- Don't be negative - your children can learn from the experience
- Support groups can help
 - Give information to your child's school
 - Link up with other families who might be facing similar issues
 - Use generic help - like children's centres
 - Allow children to speak their mind even if it's difficult
- Don't put pressure on - don't have too high expectations of your non-disabled child

Contact a Family is a charity for families with disabled children and has an excellent selection of resources on its website www.cafamily.org.uk (Helpline **0808 808 3555**)

Carers Trust runs a dedicated website for siblings/young carers www.youngcarers.net (**0844 800 4361**)

Sibs (www.youngsibs.org.uk or **01535 645 453**) is a group working to help siblings of those with additional needs.

CarersNet (www.carersnet.org) is a website for the Coalition of Carers in Scotland. It has information on young carers projects in Scotland

Sibling Support Project (www.siblingsupport.org) is an American-based siblings information website. The resources are applicable to the UK.

There are also a number of books available specifically for siblings, parents and professionals. Check online or with your local bookshop.



out & about

Since the 1995 Disability Discrimination Act, businesses must by law provide disabled access to their premises, or if this cannot be achieved, provide the service in some other way.

Most cinemas, especially modern multiplex cinemas, offer good facilities for people with ataxia and other disabilities. Details can be found on their websites.

The Cinema Exhibitors' Association Scheme
(www.ceacard.co.uk or 0845 123 1292)

means supporting cinemas issue a free ticket to carers accompanying a disabled person. A card can be applied for online (at the address above) and it lasts for three years.

In recent years, there has been a lot of pressure on the Government to make sure all public transport has disabled access. This means that most public transport is accessible for people with ataxia. People with ataxia may be eligible for reduced rates such as the

Taxi Card Scheme in London
(www.londoncouncils.gov.uk/services/taxicard or 0845 415 4156)
and the **Disabled Persons Railcard**
(www.disabledpersons-railcard.co.uk or 0845 605 0525)

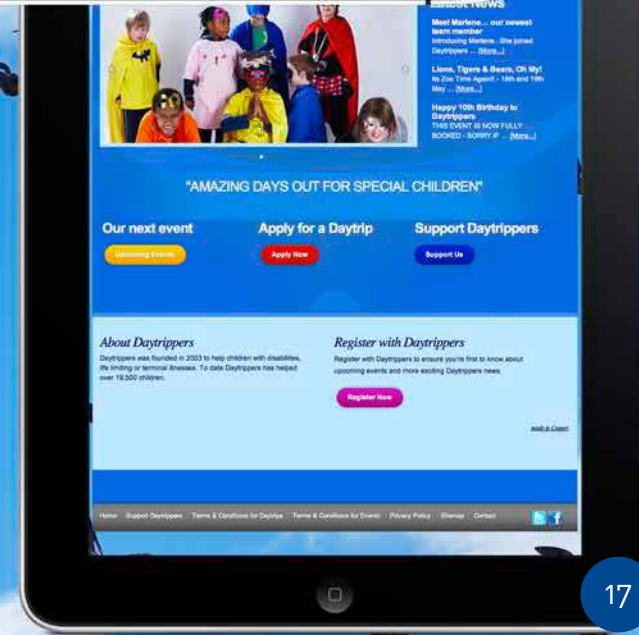
These allow people who are unable to use other kinds of public transport to travel at a cheaper rate using taxis or trains. For an extensive guide to access on public transport contact the **Disabled Living Foundation** (www.dlf.org.uk or 0300 999 0004)

www.disabledgo.com

is one of the many websites which researches individual businesses across the UK to provide reliable information about how accessible they are for wheelchair users.

Many charities organise events for disabled people, including a charity called **Daytrippers** (www.daytrippers.org.uk or 020 7758 0030) which works to allow young disabled people to enjoy fantastic trips and venues such as theme parks.

See also sections on Ataxia UK conferences and Branches and support groups.



leisure & holidays

There are many play schemes running across the UK for children with additional needs.

These can provide new experiences, the chance to meet children in a similar situation and fun activities to enjoy. Details of schemes in your local area can be found by contacting the local council.

Over the Wall is a national UK charity which provides life-changing experiences to children and young people aged 8-17 who are affected by serious and life-limiting illnesses. They do this by offering free activity camps specifically developed to foster coping, resilience, self-esteem and confidence. They give children a week of experiences that are memorable, exciting, fun and empowering, in a physically safe and medically sound environment. More details at www.otw.org.uk

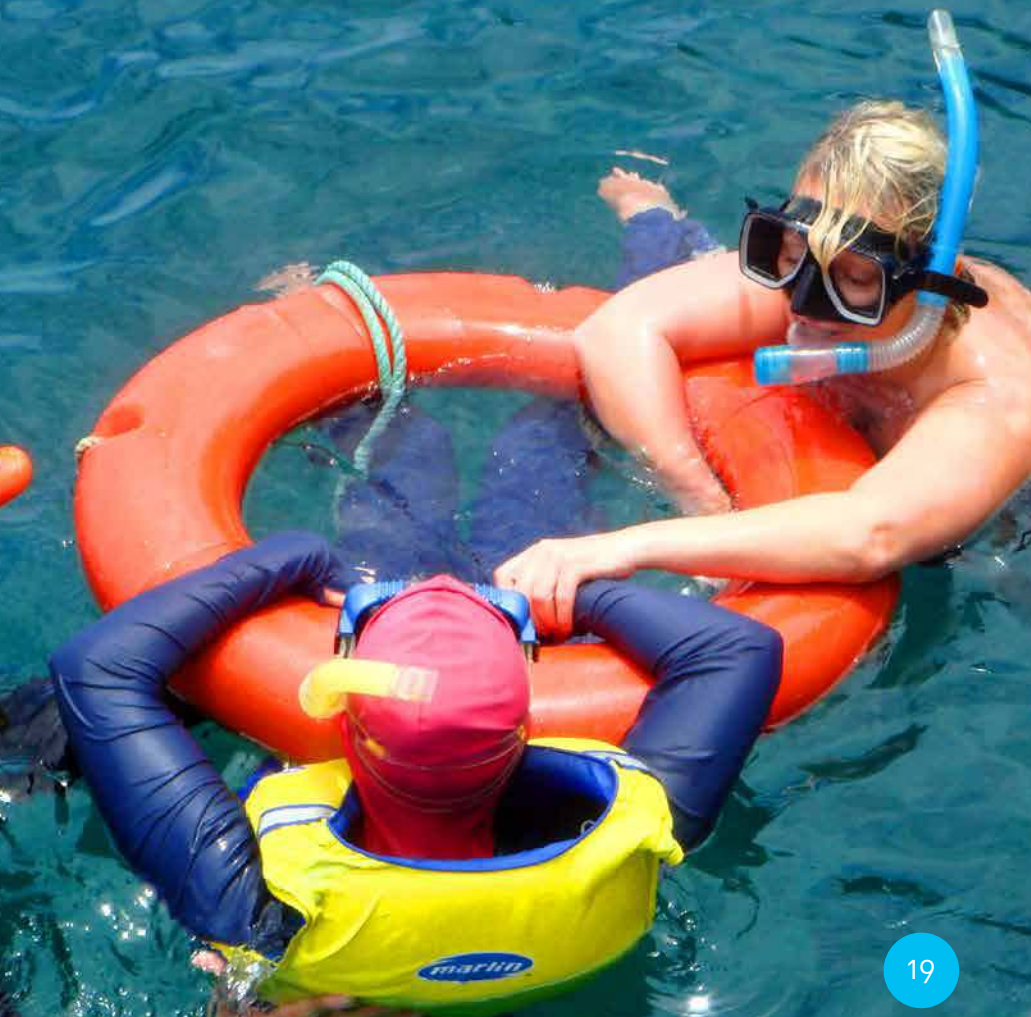
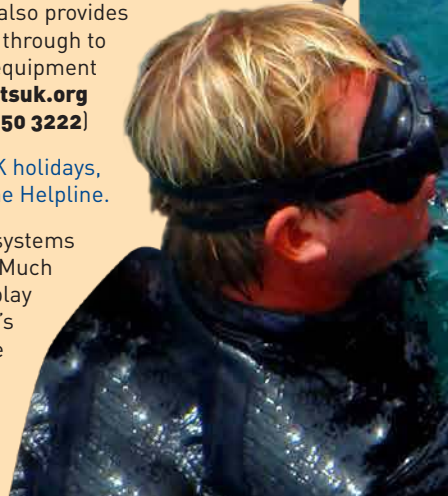
Tourism for All is the UK's central source that provides information on all aspects of holiday and travel in this country and overseas, accessible to all regardless of age or disability (www.tourismforall.org.uk or 0845 1249971)

Travel agencies and tour operators are forbidden from treating disabled customers less favourably because of their disability. However, this only applies to agencies operating within the UK, although other countries may have similar laws and regulations.

RADAR, now known as **Disability Rights UK**, produces holiday fact packs on all aspects of holidays covering holidays in the British Isles and holidays and travel abroad. It also provides information on insurance through to hiring portable equipment (disabilityrightsuk.org or 020 7250 3222)

For a more extensive leaflet on UK holidays, please contact the Helpline.

Special Effect adapts computer systems to make them accessible to all. Much more than just being able to play games, they increase a child's ability to interact and communicate (specialeffect.org.uk or 01608 810 055)



“ I remember walking with my daughter arm in arm thinking how inconvenient this was for me, in a window I saw our reflection and realised that it is FAR more inconvenient for her, she has this disability for the rest of her life every moment of the day, so I am happy to do whatever it takes to be sympathetic and help her.

sports

Taking up a sport can be a great way to meet new people as well as a fantastic way to stay active.

The English Federation of Disability Sport
(www.efds.co.uk or 01509 227 750)
can give information on local events.

Swimming

Swimming is a great exercise and can be an enjoyable way to relax for people with and without ataxia. Many public swimming pools are adapted to meet the needs of a person with ataxia and are equipped with hoists and lifts to help people in and out of the water. Check with the individual pool to find out about their accessibility.

Many sports can be adapted to allow people with conditions like ataxia to take part. This is reflected in the increase in the range of sports at the Paralympics.

Wheelpower

(www.wheelpower.org.uk or 01296 395 995)

is the national organisation for British Wheelchair Sport. It can provide you with in-depth information, from what sports are suitable for those in wheelchairs to specialist equipment used in wheelchair sports.



“Despite my diagnosis I wasn't put off riding, in fact it has helped me to keep healthy and mobile. Until the age of 18, I competed with my local pony and riding club, enjoying dressage, show jumping and cross-country. Since then, I have turned to dressage, a safer option given my worsening health. Horse-riding and the physical activity that goes hand in hand with it, is what is keeping me walking. But more than that, it has given me a reason to keep fighting.



Photo courtesy of Jane Suter

“When my child falls over, I don't immediately rush to pick them up, I don't fuss over them, the deal is that they let me know if they need me. I try to remember that they find doing any kind of activity more tiring than someone without ataxia, so I have to slow down to their pace and make it enjoyable for them.



Helen Kearney won 3 Olympic medals for horse-riding in London 2012.

(Diagnosed with

Friedreich's ataxia as a child)

Photo courtesy of Ballymore Bugle

walking aids

It is best to consult your GP or occupational therapist when considering the use of a walking aid.

Disabled Living Centres have a wide range of equipment and can give advice and information.

For your nearest centre, contact Assist UK (www.assist-uk.org or 0161 832 9757)

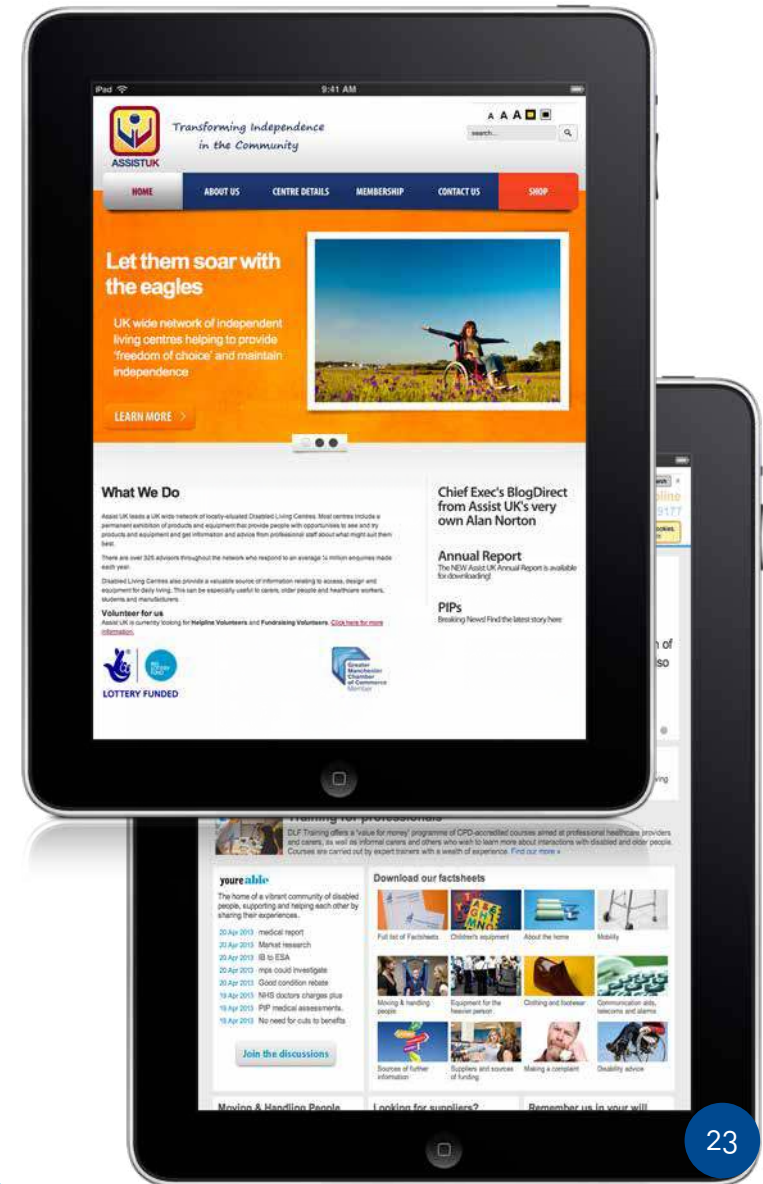
Both a walking stick and frame are suitable for those who have some ability to stand and walk but need help keeping their balance. A walking frame offers more stability and support than a stick alone. Frames can often be folded to transport (and have other additional features).



The Disabled Living Foundation (www.dlf.org.uk or 0845 130 9177) offers factsheets on the various aids and equipment available.

There are other forms of mobility aids (gait trainers and scooters) that can be obtained through the NHS, via a physiotherapist or occupational therapist.

“ Our first accessory was a wheely zimmer frame called 'pushy pants'; next we have a very petite mobility scooter called 'the combine harvester'; this is fantastic for school. These are things for my daughter who is presently 17. I don't imagine it being quite so easy if you are a boy. My son 19 lives in Bristol, has a walking stick, more to let people know he is not drunk. He is getting a battery powered tricycle, as he finds taking a taxi everywhere too expensive!



Madeleine,
mother of three
children with
ataxia

wheel chairs

Eventually it might be necessary to consider a wheelchair. The choice of manual and electric wheelchairs is forever expanding.

Technological developments mean chairs can be made stronger, faster and lighter.

The different types of wheelchairs include sports, standing and transport.

When looking for a suitable wheelchair, factors such as age, needs and abilities have to be considered.

The cost of **manual wheelchairs** varies depending on materials used and whether it's made to measure (from £100 to around £4,000).

Electric wheelchairs also vary in price depending on technology involved. The average price is around £3,500.

Standard wheelchairs are available through the NHS though they tend to be older and heavier models.

It is best to be assessed by an occupational therapist to find the most suitable wheelchair for your needs and requirements.

Wheelchairs for young people

Go Kids Go! (formerly The Association of Wheelchair Children) provides wheelchair skills training. The free courses equip young wheelchair users with the skills to become independently mobile.
www.wheelchairchildren.org.uk or www.go-kids-go.org.uk Tel. 01482 887 163

Other sites:

Action for Kids (www.actionforkids.org)
KIDS (www.kids.org.uk)
MERU (London and SE only) (www.meru.org.uk)

“ I wanted a young trendy wheelchair which was built for my small frame as most adult wheelchairs were too big and cumbersome while children's chairs were too small or designed specifically for children with their colour schemes. My solution after much thought and searching was a Quickie Helium (it cost the earth and a local dealer was hard to find) but I ended up with a small 15" wide purple/black chair which fits most places.

Taryn (25)



driving

Learning to drive is a great way to get mobile and it can give the freedom to travel whenever and wherever you want.

In most cases, cars can be adapted to your needs so that they are both practical and safe for you to drive.

Although the minimum age for learning to drive is normally 17, if you are receiving Disability Living Allowance at the higher rate (mobility component), you can drive at 16.

Many independent driving schools such as **BSM** employ specialist trainers who are able to tailor their lessons to meet the needs of someone with a condition like ataxia.

The Queen Elizabeth Foundation Centre
(www.qef.org.uk or 01372 841 100)

provides specialist tuition and motoring advice for people with disabilities, so that you can learn to drive in a safe and controlled environment.

Motability

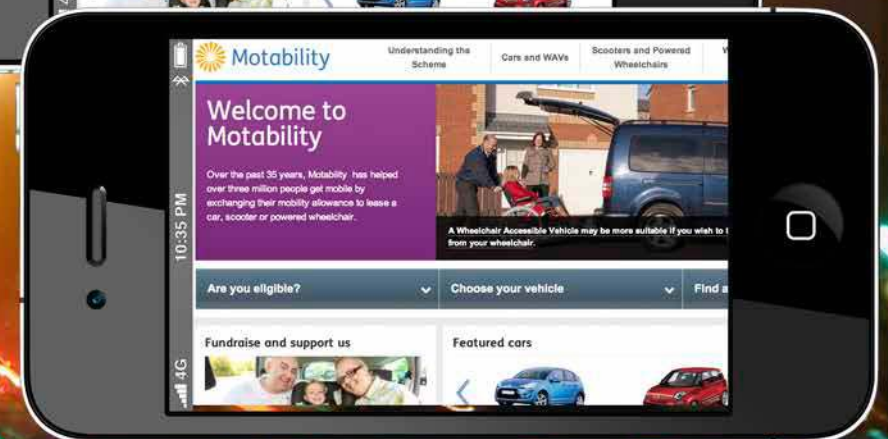
(www.motability.co.uk or 0845 456 4566)

is a national charity set up to assist people with their mobility needs. It directs and oversees the Motability Scheme which enables disabled people to obtain a car, powered wheelchair or scooter by using their government-funded mobility allowance.

Another charity is **Disabled Motoring UK**
(formerly Mobilise) www.disabledmotoring.org or 01508 489 449
for anyone who drives and has a disability
- it provides information and promotes personal mobility.

Many people with ataxia may be eligible for the **Blue Badge Scheme**.

This gives parking concessions for drivers or passengers who have problems walking. It allows badge-holders to park close to their destination. To apply for this concession, contact the social services department of your county or local authority. To find out more about this scheme visit: www.gov.uk



assistance dogs

Assistance dogs are specially trained to help disabled people carry out everyday tasks which they would otherwise find difficult.

Some people with ataxia find that having an assistance dog helps them retain their independence, as well as being a great companion.

Dogs can be trained to carry out a variety of tasks in order to help people live as comfortably as possible.

These can include opening and closing doors, reaching up to shop counters, carrying a shopping basket or even emptying the washing machine.

Assistance Dogs UK

is a group of charities working to train dogs to help disabled people live independently. This includes:

Support Dogs

(www.support-dogs.org.uk
or 0114 261 7800)

Canine Partners

(www.caninepartners.org.uk
or 08456 580 480)

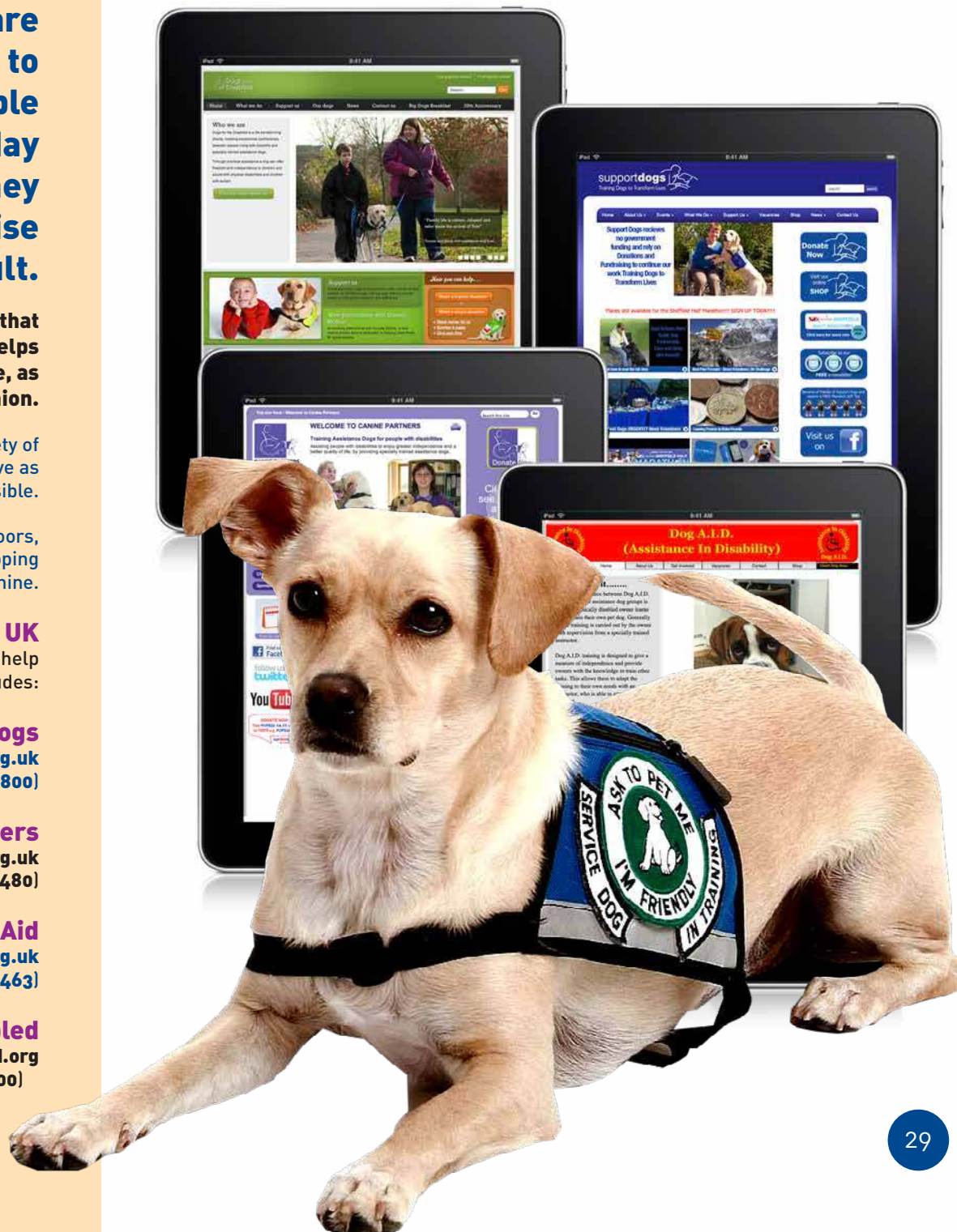
Dog Aid

(www.dogaid.org.uk
or 01543 899 463)

Dogs for the Disabled

(www.dogsforthedisabled.org
or 01295 252 600)

Dogs for the Disabled offers a service to those under 16 known as **Pals with Paws**. After a successful application, you are matched with the right dog for your needs and start training together as soon as possible.



preparing for adult life

There is a range of solutions when considering how someone with ataxia will live in adult life.

Some parents redesign the family home to enable an element of independence, other young people with ataxia prefer to live completely independently and employ personal assistants to enable them to do so.

The **Independent Living Fund (ILF)** is dedicated to delivering financial support to disabled people and advancing standards of independent living (www.dwp.gov.uk/ilf). It is part of the Department for Work & Pensions.

If you or someone you care for gets help from social services, you can apply for direct payments. These let you choose what services to buy and engage people to supply them, either yourself or through an agency, instead of getting them from your council.

Contact a Family (www.cafamily.org.uk) has produced a detailed guide on **Preparing for adult life and transition** that discusses formulating a transition plan, which ideally should start around a child's 14th birthday (Year 9). It is an inclusive process and can cover issues such as:

- **Making friends and having a social life**
 - **Sexual relationships**
- **Financial implications of leaving home**
- **Getting enough help at college or university**
 - **Ageing parents**
 - **Personal care**

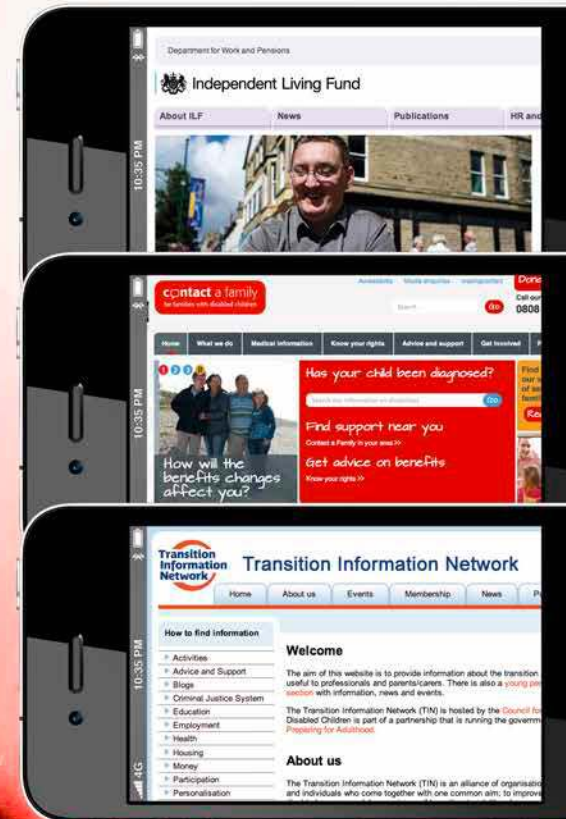
The **Transition Information Network** (www.transitioninfonetwork.org.uk) is an alliance of organisations and individuals who come together to improve the experience of disabled young people's transition to adulthood.

Work

Many people with ataxia (including Friedrich's ataxia) have successful careers and offer excellent role models to younger people. They can be encountered at our conferences and events or through our social media (see below)

A **Disability Employment Adviser (DEA)** at the local Job-centre can help find a job or gain new skills and tell you about disability friendly employers in your area. They can also refer people to a specialist work psychologist, if appropriate, or carry out an 'employment assessment'.

Careers Information and Advice for Young People (www2.cxdirect.com or **0800 100 900**) is aimed specifically at young people aged 13-19.



getting support

Ataxia UK runs a Helpline:
0845 644 0606,
open Monday - Thursday,
10.30am to 2.30pm or
helpline@ataxia.org.uk.

It is the first port of call for all questions related to ataxia.

Ataxia UK is a membership organisation and you can join for free today. Our volunteers run a national network of Branches and support groups which are an excellent social forum to meet and share experiences. New Branches are set up each year, especially if there is no group near you at present.

Visit our website for details of a branch or support group nearest to you.

We have an active Facebook group (**Ataxia UK**) and a group just for parents to chat online in private (it is connected to the Ataxia UK Facebook group).

Health Unlocked (www.healthunlocked.com/ataxia-uk) is an online forum that is set up to allow people with ataxia and carers to share experiences and ask each other questions about health and well-being.

Chat rooms

A number of international chat rooms exist, including:
groups.msn.com/ataxiachat2002
 and
internaf.org/ataxiasouthafrica@uk.msnusers.com

Virtual ataxia

There is also a 'virtual' branch of Ataxia UK that meets to chat online on Tuesdays from 7-8pm and on Sundays at 4.30pm. You can find it here (there's no need for the 'www.'): health.groups.yahoo.com/group/virtualataxia
 Support is by email only to cookealice@hotmail.com

Seminars & videos

All About Ataxia

seminars are aimed at those who have been recently diagnosed with ataxia (within the last 2 years). Run by trained volunteers the days will give patients and carers information about the clinical and practical implications of ataxia. Please contact the **Helpline** for further information.

There are a number of videos aimed at young people and those affected by ataxia on our YouTube pages:
www.youtube.com/user/AtaxiaUKonline
 and www.youtube.com/user/AtaxiaUKvideos

“

I set up a Branch to help others who may worry about their ataxia and think they are alone.

Personal websites

Several people with ataxia run their own websites, including:

Katie Henderson:
www.ohboth.co.uk

Matthew Law:
www.matthewlaw.co.uk

Millie Mae Ormsby:
www.milliemae.world.co.uk



Nancy,
Ayrshire

confer ences

**Ataxia UK
currently runs a
Regional
Conference
and an Annual
Conference
each year.**

**The locations vary to
help people from
different parts of the
country attend.
The number of people
attending grows with each
passing year.**

Our Conferences are an opportunity for people affected by ataxia to meet and chat about their experiences, as well as learn about the latest developments in research and ask questions to neurologists with expertise in ataxia.

To find out about
upcoming dates and places,
please visit our website:
www.ataxia.org.uk
or call **020 7582 1444**

“ It was my first conference
and my first chance to
meet other people with ataxia
outside my immediate family.

*It proved emotional, informative
and inspirational ... all of those
things at different times.*

“ Excellent way of sharing
experiences.

*Family members need support in
coming to terms with the demands
of having a family member with
ataxia.*



ataxia a parents' guide



Caring today
Researching for tomorrow

Ataxia UK is the national charity
that supports everyone affected by ataxia.

Helpline: **0845 644 0606**
helpline@ataxia.org.uk

Office: **020 7582 1444**
office@ataxia.org.uk

Online: **www.ataxia.org.uk**
www.healthunlocked.com/ataxia-uk

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

With thanks to

**Changing the world
for children with genetic disorders**



Ataxia UK works across the whole of the UK and is a charity registered in Scotland
(No. SC040607) and in England and Wales (No. 1102391) and a company limited by guarantee (4974832)