

(21) Parents - Transition into young adulthood

Growing up

For many children, their epilepsy will continue into adulthood. During their transition time from childhood into young adulthood seizure frequency and patterns may change, which may be linked to changes in hormone levels.

Transition to adult hospital services

Transfer to adult epilepsy services will usually happen around the ages of 16-19, or when a child leaves school. A child aged 15 or 16 at diagnosis will often be referred directly to an adult neurologist cutting out the transition phase.

The move to adult services can be unsettling as it disrupts the usual routines and familiar faces. It can also mean travelling to a different hospital. Some hospitals have a transfer clinic where families can get to know medical staff of the adult team.

Transitioning into adult epilepsy services is usually a good opportunity to review a child's epilepsy care and medication taking into account all the physical, emotional and psychological changes that are happening to a child.

Any child attending a teenage clinic will be entitled to see their consultant or other specialist without their parents and make their own decisions about their health. To prepare a child for this, it helps to involve them as early as possible into any decisions around their treatment.

Lifestyle changes

Teenagers will want to make their own lifestyle choices and develop their own interests. To help a child make informed and balanced decisions they need to be

aware of possible seizure triggers, particularly the risk of not taking their medication, or taking drugs and drinking alcohol. An older child may prefer to talk about these issues with an epilepsy specialist nurse rather than their parents.

There is also literature specifically written for teenagers addressing many of these issues, such as our own teenage guide 'A Guide to getting on with life', which can be downloaded from our website www.epilepsyscotland.org.uk.

Teenage girls also need to start thinking about contraception and pregnancy. Sexually active girls need to be on the right contraception, ie one which does not interfere with her anti-epileptic drugs and vice versa. An epilepsy specialist nurse will be able to advise further.

Any young woman thinking about starting a family should speak to an epilepsy specialist nurse first to make sure they are on anti-epileptic drugs which do not harm an unborn baby.

Transition planning at school

When a child approaches school leaving age, usually between the ages of 16-18, attention will turn to vocational training or further education. Formal planning should be started by the school / education authority, who will liaise with specialist agencies. Proper transition planning involves giving a child the kind of support that will prepare them for leaving school such as training on life skills and confidence building or finding a work placement.

When a child turns 16, the Additional Support for Learning Act gives them their own rights, and education authorities must take into account a child's views.

Schools will usually arrange for careers advice for pupils a few years before school leaving age. This is often offered at second grade to help a child make the right choices of standard grades with a view to a future career. More specific careers advice will then be offered as a child reaches school leaving age.

Making the right career choice

Having epilepsy does not mean a child will be unable to have a career or a job. In fact, the majority of people who become seizure free on anti-epileptic drugs usually pursue their career aspirations just like anyone else. Under the Equality Act, the Armed Forces are the only employer allowed to impose a ban on anyone who has had a seizure after the age of 5 (there are some minor exemptions).

If a child continues to have seizures in young adulthood, health and safety restrictions will need to be considered when thinking about a career or job choice. Apart from the Armed Forces, any other profession or employer will need to assess the person with epilepsy on a case by case basis. Many professions, however, have their own regulations and restrictions, such as the police, fire service, nurses, doctors, pilots or teachers.

Certain careers and jobs will not be possible if a child's seizures are frequent and unpredictable. These may include working in the construction industry or working at heights. Office based work tends to be more suitable for someone with uncontrolled seizures.

A guidance teacher will usually put a child in touch with a careers adviser for an initial chat. Not all careers advisers know about epilepsy or understand how it may affect a child on a daily basis. Parents can help by providing this kind of information to anyone who will advise their child on career choices. A parent can also be part of the meeting with the careers adviser but they will need their child's permission for this.

There's more information on choosing the right career on the Skills Development Scotland's [My World of Work](http://www.myworldofwork.co.uk) website www.myworldofwork.co.uk.

Most local Jobcentre Plus offices have Disability Employment Advisers who can provide support to anyone finding it difficult to get a job. Find your nearest Jobcentre Plus at www.gov.uk/contact-jobcentre-plus.

Further or higher education

When a child goes to college or university, these institutions are required by law (Further and Higher Education Act 2005) to take into account a child's educational support needs. The kind of support offered to students with a disability differs from college to college. Every college will have a disability adviser or learning support co-ordinator. If you have chosen a specific college, you and your son / daughter can arrange to speak to the disability adviser in advance so any additional support or special adjustments can be coordinated.

Specialist residential colleges

A child with complex needs beyond epilepsy may need to attend a specialist residential college for further education. There are over 50 specialist residential colleges in England and Wales but none in Scotland, which means considering boarding outside Scotland.

In Scotland it is up to each local authority to decide whether to fund further education in a special needs college. To try and access funding, you should ask your social work department for an assessment of your child's needs which includes access to appropriate education. Some local authorities may agree to part fund further education in a specialist college.

Open or distance learning

Open or distance learning is a further option if a child's needs are complex. The Open University has a wide range of courses on offer. For more information, visit their website www.open.ac.uk.

Transition to adult social work services

Transfer to adult services will usually begin around the age of 16. Until a child turns 18, their needs will be assessed under the Children (Scotland) Act. After the age of 18, different pieces of community care legislation will apply. This will usually mean

new faces and new assessments. In the run up to the transition, social work have a role in making this process as easy as possible by providing parents and the child with all the necessary information on available adult services.

When planning your child's transition with social work, it is important not to restrict planning to the services you know exist. Focus instead on all the needs of your child, indicating any services you think your child would need to be fully supported. If social work cannot provide all essential services, apply for direct payments or any other benefits your child may be entitled to. This may allow you to buy in those services that you consider to be essential for your child.

Turning 16

Once a child reaches 16 in Scotland, they are an adult in the eyes of the law, able to make their own decisions about their finances, lifestyle, career and wellbeing. Having epilepsy does not usually affect a child's ability to make these decisions.

Guardianship order

If a child has more complex needs and may not be able to look after their own affairs, parents can apply for a Guardianship order under the Adults with Incapacity (Scotland) Act 2000. This order appoints a person (guardian) to look after someone's financial and physical / psychological affairs (but it may not need to be both) because that person is incapable or unable to make these decisions themselves.

Parents can instruct a solicitor to deal with all the paperwork. A guardianship order can be applied for three months in advance of a child's 16th birthday, which will ensure that decisions can be made as soon as a child turns 16. A Guardianship order will only be agreed to by a Sheriff if it is necessary, and can be for three years, or, in some circumstances, for an unlimited period of time.

You can contact the Office of the Public Guardian (Scotland) on 01324 678300 or visit their website www.publicguardian-scotland.gov.uk for more information. Apart from a solicitor, your local Citizens Advice Bureau can also provide further advice on this important issue.

Becoming more independent

A child will want to become more independent as they grow into a young adult and may want to go to university or move away from home for good. Even a young adult with more complex needs will want to gain their independence.

Some parents may no longer be able to look after an adult child with complex needs, particularly as they get older and if they develop their own health problems.

The kind of accommodation available for adults with complex needs varies from supported housing to mainstream housing which has been adapted and made accessible. A local authority will have a Supporting People Team, which looks after adults needing help and support with living independently. The team helps with the planning process and will also fund suitable accommodation, subject to assessments of needs.

A social worker will be the first point of contact to discuss the various options available. Some voluntary and private sector organisations also provide support for independent living and it is worth doing some independent research on this.

Learning to let go

As a child grows into a teenager and young adult, parents need to gradually hand over responsibilities to their child and others. This will be a process of slowly building trust between a parent and child over time. By being supportive and encouraging a child to assume responsibility for their own life, parents will help their child become as independent as possible.