

Family Factsheets

Transition to adult services

Advances in medicine and technology mean that more children with life-limiting or life-threatening conditions are living into adulthood, often with complex and unpredictable health needs.

It can be a very worrying time for parents and carers as their child moves from familiar children's services to new adult services and is expected to take on decision-making responsibility for themselves. This factsheet aims to help parents to think about the different elements of transition that need to be planned for and to provide tips to help the process feel as smooth as possible.

When does transition start?

Transition is not a single event, but is a gradual process of supporting a young person and their family through their teenage years and into adulthood, building up their confidence and ability to manage the care and support they need. The process should ideally begin around the age of 14 years, in England tying in with the Year 9 school annual review. A good transition should build on the young person's strengths and wherever possible work with the young person themselves to plan for how they can meet their aspirations in life.

It should also involve you as parents/carers and support you to understand the changes in your rights as your child reaches

the legal age of adulthood. The legal age of becoming an adult is 16 years in Scotland but 18 years across England, Northern Ireland and Wales. Transition is a long process and young people often still want the support of their parents in making decisions. The age at which your child enters adult services is likely to vary depending on where you live and your circumstances. Each service may have a different age when they transfer care from children's to adults. Some children will access aspects of adult health care before they are 18, while others may still be supported by paediatric services after their 18th birthday. Ask each service what age the transfer will take place, who is taking over and how they are going to introduce you to the new service.

Making decisions and the Mental Capacity Act 2005

When your child reaches the age of adulthood, statutory agencies will consider them as an adult, regardless of their mental capacity. If your child has the capacity to make decisions for themselves, it is crucial that as parents, you encourage them to become more independent, so that there is a move from parent-led to individual-led decision making. It is important that you are aware of the changes to your role in decision-making for your adult child. For decisions about health and welfare, the Mental Capacity Act 2005 (England and Wales) applies to everyone over the age of 16 years. For further information, read our factsheet on the Mental Capacity Act.

www.togetherforshortlives.org.uk/families/information_for_families/4980_the_mental_capacity_act

Making plans

During transition, young people should be supported by staff working across agencies so that they can plan for the care that they will need from health, social, education, housing and employment services. Many young people living in England will already have an Education, Health and Care Plan (EHCP) in place that sets out the support that they will need across these agencies. The EHCP assessment process gathers information from all those supporting your child to inform how the desired outcomes can be best met. The EHCP should be agreed in partnership with yourselves and should detail costs and timescales. This plan follows your child as they change services and should be reviewed should your circumstances change.

Standards in transition

Throughout the transition process, five key standards should be met to ensure that all young people are supported to achieve a good transition.

Standard 1	Every young person from age 14 should be supported to be at the centre of preparing for approaching adulthood and the move to adult services. Their families should be supported to prepare for their changing role.
Standard 2	Every young person is supported to plan proactively for their future. They are involved in ongoing assessments and developing a comprehensive, holistic plan that reflects their wishes for the future.
Standard 3	Every young person has an end of life plan which is developed in parallel to planning for ongoing care and support in adult services.
Standard 4	Children's and adult services are actively working together to ensure a smooth transition.
Standard 5	Every young person is supported in adult services with a multi-agency team fully engaged in facilitating care and support. The young person and their family are equipped with realistic expectations and knowledge to ensure confidence in their care and support needs are being met in the future.

Scotland has The Principles of Good Transitions 3, a framework to inform, structure and encourage the continual improvement of support for young people with additional needs between the ages of 14 and 25 who are making the transition to young adult life.

<https://scottishtransitions.org.uk/summary-download/>

Health

For young people with complex and life-threatening health conditions, their transition to adulthood will need to be underpinned by strong partnership working between children's and adult health services. This may involve community, hospital and hospice care teams. From the age of 14 years, healthcare professionals should begin to discuss with you and your child the plans for transferring to adult healthcare. It is helpful if your general practitioner (GP) is involved as they can be a key point of contact even if they have not had much contact with your child up to this point.

Healthcare professionals will also change; with your GP, Continuing Health Care or District Nursing teams playing an increasingly significant role. Your child should be introduced to new staff and agencies as part of the transition process and you should have opportunities to discuss what changes to expect with them.

People aged 14 and over who have been assessed as having moderate, severe or profound learning disabilities, or people with a mild learning disability who have other complex health needs, are entitled to a free annual health check which can be arranged through your GP practice.

There are likely to be some services that have supported you throughout your child's life that may not be available to you as they become an adult. For example, if you have used a children's hospice, this may not be available once your child reaches 18. Every children's hospice is different and will have a different upper age limit – so do check. Whilst more and more adult hospices are beginning to play a role in supporting young people, it is important

to remember that while they can offer a great range of support, not all of them are able to offer the range of services such as short breaks or some of the therapies for young people with very complex health needs that you may be used to.

It is really important to have plans in place which enable the transition process to remain focussed on your child's wishes. Having parallel plans will help meet the needs and wishes of your child should their health remain stable but also for times when their condition may deteriorate. These should be reviewed regularly. It is also important to check that any documented wishes for your child's treatment are in a format that is accepted by adult services and that copies are given to the GP and uploaded to the local ambulance service. This is important in any emergency as the ambulance service will actively treat unless written and signed instructions are seen.

Social care

For many young people, their social life and relationships with friends are very important and they will need support to enable them to lead the social life that they want. Your local adult social care team are responsible for ensuring that a care package is in place. The care plan defines exactly what your child needs in the way of care, services or equipment to live their life in a dignified and comfortable manner.

You may also find that there will be changes to the grants or benefits that you receive. It is possible that income coming into your household and other non-finance benefits (such as housing and transport) will be

affected. However, you will have new rights under the Care Act which may entitle you and your child to new benefits.

Education

There are various choices available to young adults after 16 years of age and your son or daughter may want to consider one of the following routes:

- Full-time education, such as school, college or home education
- Work-based learning, such as an apprenticeship
- Part-time education or training, if they are employed, self-employed or volunteering for more than 20 hours a week.

Specialist colleges offer tailored curricula for young adults with profound and multiple learning difficulties (PMLD). Further information is available on the Natspec website. <https://natspec.org.uk>

Housing

There are a range of options to enable your son or daughter to live in the setting that best suits them and with the right kind of care package. This might be at home with you, at university, in residential/supported living or living independently.

If you live in England, your local authority will publish its Local Offer which should contain information about different housing options. It should also detail where to get financial and other support (such as a personal assistant, assistive technology or modifications to a home) and more detailed advice on accommodation and support.

Employment

As your child moves into adulthood they may want to enter work or find other opportunities such as volunteering or mentoring. There are a range of courses at colleges and work-based learning providers who can offer opportunities to develop work and vocational skills. For further information about supported employment visit the British Association for Supported Employment website.

www.base-uk.org

What is important is that all these services, in the children's and adult sector work together to ensure that there is a smooth handover process.



Settling into adult services

You should have confidence that your child has a care package that allows them to live their life to their maximum potential and which meets their physical, emotional and social needs. Their needs will change over time, so it's important that you work closely with professionals to adapt the package to best meet their needs and enable them to reach their full potential as adults.

National variations

England and Wales

Eligibility for adult continuing health care and adult social care funding must be established by the appropriate adult team. This can be from age 17 years upwards, but transfer will only happen at 18 years.

Preparing for Adulthood is a programme funded by the Department for Education to provide expertise and support to local authorities and their partners to improve the transition of young people with special educational needs and disability (SEND) as they move into adulthood. The Preparing for Adulthood website hosts a wealth of information and resources.
www.preparingforadulthood.org.uk

Each local authority in England and Wales has a legal requirement to provide a local resource for children and young people from birth to 25 years, with special needs. To find out more about the services available to support you, search for 'Local Offer' on your local authority website.

The Council for Disabled Children has produced a factsheet which explains the two pieces of legislation which impact on disabled young people – The Children and Families Act and the Care Act.
<https://councilfordisabledchildren.org.uk/help-resources/resources/children-and-families-act-and-care-act-factsheet>

Scotland

The Additional Support for Learning (ASL) Act should be followed as this sets out the processes and timescales for transition. In Scotland, the legal age of an adult is 16 and at this point it is important to assess a young person's capacity to make decisions about their life, including their care and treatment. The Adults with Incapacity Act (Scotland)

gives another person the legal power to make decisions on the adult's behalf.

www.gov.scot/Topics/Education/Schools/welfare/ASL

The Scottish Transitions Forum hosts information for those living in Scotland and houses the Principles of Good Transition 3 document.

<https://scottishtransitions.org.uk/>

http://scottishtransitions.org.uk/blank/wp-content/uploads/2017/01/complete-POGT3_A4-version.pdf

Northern Ireland

In Northern Ireland, 'A Strategy for Children's Palliative and End of Life Care 2016-26' (Department of Health 2016), recommends that every child with palliative care needs should have an agreed comprehensive transition/discharge plan involving the hospital, community services and the family as set out in 'The Integrated Care Pathway for Children with Complex Physical Healthcare Needs', (DHSSPS 2009). A transition plan should be agreed at least six months prior to the planned transition.

Helpful resources

Below are a number of resources and organisations that can help you plan for your child's transition but if you have further questions, please email:

info@togetherforshortlives.org.uk

or call **0808 808 100**.

Moving to Adult Services: What to Expect

An interactive guide for young people making the move to adult services.

http://www.togetherforshortlives.org.uk/assets/0001/5480/TfSL_Moving_to_Adult_Services_Guide_FINAL_.pdf

Stepping Up

A guide for professionals aiming to ensure that all young people have a positive experience of growing up and making a good transition to adult services.

http://www.togetherforshortlives.org.uk/assets/0001/0439/TfSL_Stepping_Up_-_Transition_Care_Pathway_6.pdf

My Adult, Still my Child

Outlines the legal implications of the Mental Capacity Act 2005 (England and Wales) and the changing role that parents have in decision making.

<http://myadultstillmychild.co.uk>

Decision Making Toolkit

A resource designed to be used in partnership with young people to support them to make their own decisions and to participate in decisions made on their behalf.

<https://councilfordisabledchildren.org.uk/help-resources/resources/decision-making-toolkit-0>

Carer's assessments

Carers UK provide factsheets and information on caring for either children or adults across each nation of the UK.

<http://www.carersuk.org/help-and-advice/practical-support/getting-care-and-support>

Benefits

The following organisations provide up to date advice on benefits:

Scope

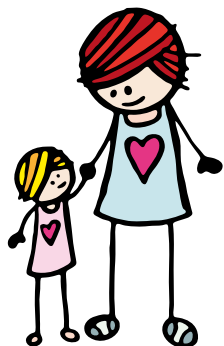
www.scope.org.uk

Turn2us

www.turn2us.org.uk

If your child would like you to act on their behalf on matters concerning their future care, this overview of Deputyships and Lasting Power of Attorney may be helpful.

www.gov.uk/power-of-attorney



Together for Families Helpline & Live Chat
10am-4pm, Monday to Friday

0808 8088 100

info@togetherforshortlives.org.uk

www.togetherforshortlives.org.uk



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