

Transition to adult services

A guide for parents



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When a child's life is expected to be short, there's no time to waste. Together for Short Lives is here to make sure the 99,000 seriously ill children and their families across the UK can make the most of every moment they have together, whether that's for years, months or only hours. We stand alongside families, supporting them to make sure they get the vital care and help that they need.

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This publication will be reviewed on an annual basis and amended as needed, at our discretion.

Contents

When Does Transition Start?	4
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Making Decisions and the Mental Capacity Act 2005	5
Lasting Power of Attorney and Deputyship	5
Liberty Protection Safeguards	6

National Policy and Guidance	7
England and Wales	7
Scotland	7
Northern Ireland	7

Together for Short Lives Standards for Transition	8
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The Three Stages of the Transition Pathway	9
Phase 1: Preparing for adulthood	10
Phase 2: Making the transition to adult services	10
Phase 3: Settling into adult services	11

Multi-agency Support	12
Health	13
Social care	15
Education	16
Housing	17
Employment	17

Helpful organisations	18
------------------------------	----

Notes	19
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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 worrying time as your child moves from familiar children's services to adult services that are new to them.

You will also have to adapt to a new parenting role as your son or daughter is expected to take on more decision-making responsibility for themselves, where they have capacity to do so. Many adult services have become more aware of the need to increase the support they provide for young people and this includes hospice and palliative care services.

This booklet aims to help you think about the different elements of transition for your child and provide tips and links to other resources to help the process feel as smooth as possible.

When Does Transition Start?

Transition is not a single event. It is a gradual process during which your son or daughter should be supported throughout their teenage years and into adulthood to build up their confidence and ability to manage the care and support they need where they have capacity to do this. The process should ideally begin from age 12 and be well underway by the age of 14. In England this will often tie in with the Year 9 school annual review. A good transition should build on your young person's strengths and wherever possible work with them 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 carers as your child reaches the legal age of adulthood. The legal age of becoming an adult is 18 years across England, Northern Ireland and Wales, but 16 years in Scotland. The age at which your child enters adult services is likely to vary depending on where you live and what is available locally, your child's condition, and your circumstances. There will be multiple transitions to organise between different specialists and services, often with differing age criteria.

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 young person-led decision making. This can be difficult for any parent, but even more so when you have a child with a life-limiting or life-threatening condition. You should feel supported by your team of professionals and encouraged to allow your son or daughter to begin to make decisions and take more responsibility for their care.

It will be helpful if you familiarise yourself with the Mental Capacity Act 2005 (England and Wales) which applies to everyone over the age of 16. This sets out the changes that will happen to your adult child in terms of decision-making about their health and welfare. For further information, read our factsheet on the Mental Capacity Act.

www.togetherforshortlives.org.uk/get-support/supporting-you/family-resources/mental-capacity-act

A resource has been produced for parents which can answer many of the questions you may have about the Mental Capacity Act

<http://myadultstillmychild.co.uk>

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.

Lasting Power of Attorney and Deputyship

When your son or daughter approaches adulthood you may want to think about applying for Lasting Powers of Attorney in order to make sure that the process is in place for making decisions on their behalf if they lose the capacity to do so. A lasting power of attorney (LPA) is a legal document that lets someone ('the donor') choose one or more trusted people ('attorneys') to make decisions on their behalf. The attorney/s does not have to be a family member. There are two types of LPA:

- property and financial affairs
- health and welfare

A Deputy is a person appointed by the Court of Protection to support someone (the client) who lacks the mental capacity to make certain decisions themselves. A deputy is appointed if someone loses mental capacity and does not have a lasting power of attorney in place.

It can be a confusing process and it may be helpful to talk to a member of your care team if you are struggling with the process. You can read more about this process in our factsheet: www.togetherforshortlives.org.uk/get-support/supporting-you/family-resources/lasting-powers-of-attorney-and-deputyship

Liberty Protection Safeguards

The Liberty Protection Safeguards provide protection for people aged 16 and above who may need to be deprived of their liberty in order to enable their care or treatment, and who lack the mental capacity to consent. The Liberty Protection Safeguards were introduced in the Mental Capacity (Amendment) Act 2019 and replace the Deprivation of Liberty Safeguards (DoLS) system. There are some key changes, one of which is that the Liberty Protection Safeguards will apply to individuals residing in domestic settings. This means that they will apply to your home or to wherever your son or daughter is living. www.gov.uk/government/publications/liberty-protection-safeguards-factsheets/liberty-protection-safeguards-what-they-are



National Policy and Guidance

England and Wales

NICE (the National Institute for Clinical Excellence) published guidelines in 2016 which set out evidenced good practice in transition for all young people moving from children to adult health and social care. These apply in England and Wales.

www.nice.org.uk/guidance/ng43

Each local authority in England and Wales has a legal requirement to provide services locally for children and young people with special needs, from birth to 25 years. To find out more about the services available to support you, search for ‘Local Offer’ on your local authority website. You can read about the SEND Code of Practice here.

www.gov.uk/government/publications/send-code-of-practice-0-to-25

Scotland

The Scottish Government has set out a commitment to provide all children, young people and their families with the right support at the right time: Getting it right for every child (GIRFEC).

www.gov.scot/policies/girfec

The Education (Additional Support for Learning) (Scotland) Act 2004 (www.legislation.gov.uk/asp/2004/4/contents) sets out the duties of education authorities and the rights of parents, children and young people to additional support for learning.

There is also a framework called ‘Principles of Good Transitions’ which aims to improve the support of young people with additional needs between the ages of 14 to 25.

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

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 at least six months prior to the planned transition.

www.health-ni.gov.uk/publications/strategy-childrens-palliative-and-end-life-care-2016-26

Together for Short Lives Standards for Transition

Together for Short Lives has developed specific standards for transition for young people with complex life-limiting health conditions which are set out in our Transition Pathway for professionals 'Stepping Up'. www.togetherforshortlives.org.uk/resource/transition-adult-services-pathway. This pathway contains three phases and five key standards which should be met to ensure that all young people with a life-limiting condition are supported to achieve a good transition.

Within each of these standards there are a series of goals which we would expect to be achieved for all young people with life-limiting conditions and their families. We have produced a 'Transition Checklist' so you can assess whether you are receiving this level of care and support. www.togetherforshortlives.org.uk/get-support/supporting-you/family-resources/a-checklist-to-a-good-transition



The Three Stages of the Transition Pathway

Transition can be seen as a journey, with three distinct phases:

Phase 1: Preparing for adulthood

Standard 1: Every young person, by the age of 14, should be supported to be at the centre of preparing for approaching adulthood and for the move to adult services. Their families should be supported to prepare for their changing role.

Phase 2: Preparing for moving on

Standard 2: Every young person is supported to plan proactively for their future. They are involved in ongoing multi-agency assessments and developing a single holistic transition plan that reflects their goals, wishes and aspirations for the future.

Standard 4: Children's and adult services are actively working together to enable a smooth transition.

Phase 3: Settling in to adult services

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 clear expectations and knowledge to ensure confidence in their care and support needs being met in to the future.

Standard 3: Every young person should be offered an Advance Care Plan (ACP) which includes planning for end of life in parallel to planning for ongoing care and support in adult services.



Outcomes for Young People

Phase 1: Preparing for adulthood

You and your family have been given the opportunity to talk to those around you about your needs and wishes for the future. A range of people have been involved and they know what role they must play in supporting you.

Phase 2: Preparing for moving on

Everything is going according to your transition plan and you are being encouraged to think about what you may want to do or where you might want to live when you become an adult. You and your family are prepared for changes to the services and support you may receive, in times of both stable and deteriorating health.

Phase 3: Settling in to adult services

You feel able to live life as an adult, as independently as you wish. You are well supported by services and able to realise the ambitions you have.

Phase 1: Preparing for adulthood

This phase will often continue over a period of three to four years, with ongoing preparation for the move to adult services and regular multi-agency assessment meetings to work out exactly how different agencies and organisations will work together to meet your son's or daughter's needs. By the end of this phase there should be a written multi-agency transition plan in place, and organisations from children's and adult services should be working together to achieve a smooth transition.

Parallel planning should continue to take place during this phase so that alongside planning for transition and future life as an adult, there is an Advance Care Plan (ACP) in place that includes your son's or daughter's end of life care wishes. It is best to start the ACP process when your young person is relatively well and not when their health is deteriorating. The ACP should be shared with relevant agencies. It can be reviewed and changed at any time.

Throughout this phase of transition there will be a growing emphasis on supporting a 'young person-centred' approach. Many parents describe how difficult it feels to 'let go' of their child, but you can feel reassured that you will always play a central role in building their confidence and abilities to make decisions. If your young person lacks capacity, you should have the documentation in place to ensure that you continue to have a central decision-making role in your child's adult life.

Phase 2: Making the transition to adult services

Children's and adult services should work together so that there is a flexible approach to meeting the individual needs of your child and their health as they approach adulthood. Transition is a fluid process, but the move into adult services should begin whether or not there are ongoing uncertainties about the state of your young person's health. Any specific healthcare needs that are identified during transition should have been discussed with the appropriate adult service in advance.

Phase 3: Settling into adult services

Once in adult services, you should feel confident that your child has a care package in place that allows them to live their life to the full and which meets their physical, emotional and social needs as a young adult. You should also be reassured that there is high quality care in place to meet their complex health needs, with access to hospice or palliative care if their health becomes unstable or deteriorates. Their needs will change over time, so it's important that you work closely with the care teams involved to review their needs and update their care package.

There are likely to be multiple professionals from different agencies involved and there should ideally be a key worker model in place so that there is overarching co-ordination of all these different professionals.

The engagement of primary care services (GP, district nurses etc) is vital to the success of young adults transitioning from children's services. The GP has the unique position of becoming the key healthcare professional for you and your family. The GP may have had little involvement with your child, so it will be important to start building a relationship with your GP practice early on, so they can be included as part of the care team.



Multi-agency Support

There are many different services that need to work together to provide support for your young person, and for you and your family. We have developed this 'Pentagon of Support' to show the five key agencies that should work together, with the young person at the centre. Good transition is underpinned by having the right health and social care in place.



Education, Health and Care Plan

During transition, young people should be supported by staff working across agencies so that they can plan for the care they will need from health, social care, and education services. Many young people living in England will already have an Education, Health and Care Plan (EHCP) in place that sets out the support 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 you and your child/young person, and should detail costs and timescales. This plan follows your child as they change services and should be reviewed should your circumstances change.

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. This can be prompted by the learning disabilities health check scheme. This is designed to encourage GP practices to identify all patients aged 14 and over with learning disabilities, to maintain a learning disabilities 'health check' register, and offer them an annual health check, which will include producing a health action plan.

The team of healthcare professionals supporting you will change as your young person moves into adult services; for example, your GP or District Nursing team may play an

increasingly significant role. You and 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.

There are likely to be some services that have supported you throughout your child's life that may not be available in the same way once your child has reached adulthood. Services are likely to be more fragmented without a paediatrician, children's hospice or palliative care team providing an 'overview' for your child. There are many positive elements to adult services, for example it can help many young people to have more freedom and choice over the care that they receive and help them to enjoy the next phase of their life as an adult. It is important to keep these positives in mind and support your son or daughter to look forward to this next phase of their life.

Continuing healthcare

As a child, your son or daughter may have received a 'continuing care package'. As an adult, they may qualify for NHS continuing healthcare, which means that the NHS fund their social care needs. This care can be provided in a variety of settings, including at home. To qualify for continuing healthcare, your son or daughter's needs will need to be assessed against a set of criteria. You can find out more on the NHS website: www.nhs.uk/conditions/social-care-and-support-guide/money-work-and-benefits/nhs-continuing-healthcare

Hospice care

If you are supported by a children's hospice, you may find that your child no longer fits their criteria once they reach the age of 18. This varies from hospice to hospice. Some have a much higher upper age limit and some of those with a younger age limit will provide a transition coordinator who can help you through the move to adult services. Adult hospices can be very different to the children's hospice that you may be used to, but many are developing their services for young people and some can offer day care or social activities, not just end of life care. It is likely that short break (respite) care is not available in an adult hospice service, although some have started to develop these services.

End of life care and parallel planning

It is important to have a documented Advance Care Plan in place which enables 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. You can read more about end of life care in our booklet. www.togetherforshortlives.org.uk/get-support/your-childs-care/end-life-care. There is also guidance from Hospice UK. www.hospiceuk.org/information-and-support/your-guide-hospice-and-end-life-care

Social care

As your child reaches their teenage and adult years, they will often want increased independence, and more freedom to spend time with friends and enjoy a social life. Some may have a boyfriend or girlfriend and want to have a sexual relationship. As part of their overall needs assessment, they should be asked about what is important for them, what they want to achieve, and what they enjoy in life. Your local adult social care team are responsible for ensuring that a care package is in place to meet your young adult's assessed needs. The care plan defines what they need in the way of care, services or equipment to live their life to the full.

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. Contact the Department for Work and Pensions to find out more: www.gov.uk/browse/benefits

Under the Care Act 2014, there may be new benefits that your young person is entitled to or which you can access as a carer. Some useful guidance on the Care Act has been developed by the Council for Disabled Children.

<https://councilfordisabledchildren.org.uk/resources/all-resources/filter/statutory-guidance/2014-care-act-easy-read>

Personal budgets & direct payments

If the local authority (in England, Scotland and Wales) or health and social care trust (in Northern Ireland) decides that you're eligible for help, you may receive funding in the form of a personal budget.

The amount of money available to spend is based on how much it will cost in your local area to arrange the care and support your child needs. You can choose how you spend your personal budget from the options below.

- Your local authority/trust manages an account and organises and pays for the support, which is either chosen by you or themselves.
- A third party manages an account, makes support arrangements and handles payments. The third party may be a local care provider or local charity.
- You can request a direct payment. You can then set up an account specifically to receive the payment and buy and organise services yourself.
- Some combination of the above; for example you pay for some services while the local authority/trust manages the rest.

In **Scotland**, having the choice of how you manage and pay for care services is known as self-directed support.

You can find further information about personal budgets and direct payments from the following organisations:

NHS: www.nhs.uk/nhs-services/help-with-health-costs/what-is-a-personal-health-budget/

Contact: <https://contact.org.uk>

IPSEA: www.ipsea.org.uk/personal-budgets-and-direct-payments

Education

An Education, Health and Care Plan (EHCP) is a legal document which describes a child or young person's special educational needs, the support they need, and the outcomes they would like to achieve up to the age of 25. The special educational provision described in an EHCP must be provided by the child or young person's local authority. This means an EHCP can give a child or young person extra educational support. It can also give parents and young people more choice about which school or other setting the child or young person can attend.

There are various educational 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>

Many of these options provide residential care and once your son or daughter leaves education there is a transition to a new setting that needs to be considered.

Housing

There are a range of options to enable your son or daughter to live in the kind of setting that best suits them and that offers 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 such as social housing, housing association accommodation, private renting, shared housing, and shared ownership. It should also detail where to get financial and other support (such as a personal assistant, assistive technology or modifications to a home) to enable your son or daughter to live as independently as possible, with the right level of care and support.

Employment

As your child moves into adulthood they may want to enter the world of work or volunteer with a charity. 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



Helpful organisations

There are many organisations that can provide support and resources to help you plan for your child's transition. We have listed a few national organisations below but if you have further questions, please email info@togetherforshortlives.org.uk or call our helpline **0808 808 100**.

BASE

The British Association for Supported Employment is the national voice for providers of specialist employment support. www.base-uk.org/home

Carers UK

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

www.carersuk.org/help-and-advice/practical-support/getting-care-and-support

Contact

A national charity that provides a wide range of information and support for families of disabled children.

<https://contact.org.uk>

Council for Disabled Children

The national body for the disabled children's sector. CDC provides a range of resources to support and empower parents.

<https://councilfordisabledchildren.org.uk>

Hospice UK

The national charity for hospice and end of life care provides information for patients and their families about end of life care and bereavement.

www.hospiceuk.org

IPSEA

Independent Provider of Special Education Advice is a registered charity in England that offers free and independent legally based information and support to help young people with all kinds of special educational needs and disabilities to get the right education.

www.ipsea.org.uk

NatSpec

Natspec is the membership body for organisations which offer specialist further education and training for students with learning difficulties and/or disabilities aged 16 to 25.

<https://natspec.org.uk>

Scope

The disability equality charity in England and Wales. Scope provides practical information and emotional support.

www.scope.org.uk

Turn2us

A national charity providing practical help to people who are struggling financially.

www.turn2us.org.uk/About-Us

Notes

Phase 1

Phase 2

Phase 3



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