

# Moving to Adult Services: What to Expect

A guide for young people with life-threatening conditions making the transition to adult services

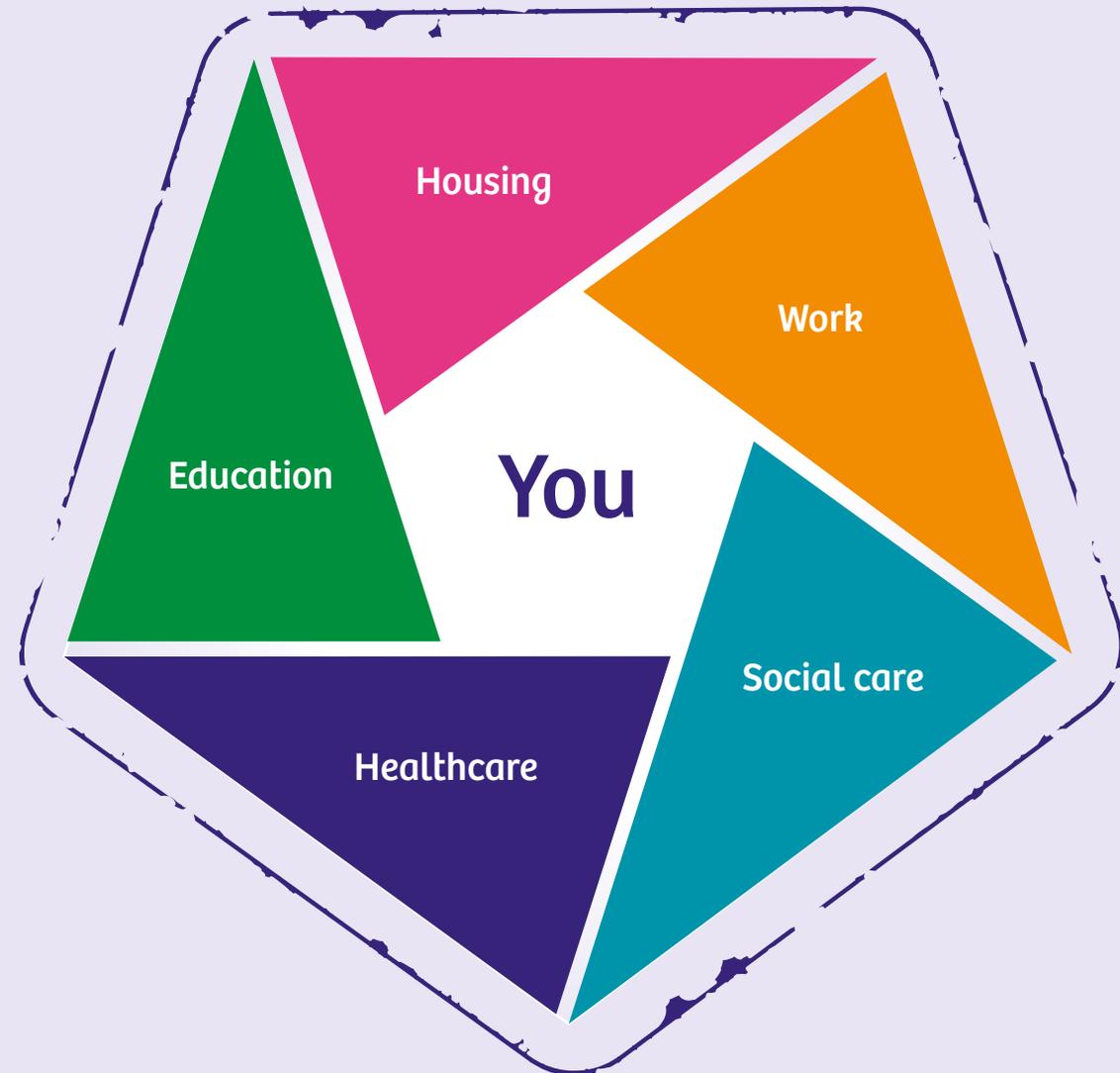
# Moving to Adult Services: What to Expect

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## Section 1: Stages of transition

## Section 2: Aspects of transition

This guide has been developed to help young people from the age of 14 years with life-threatening conditions to know more about what to expect when they move to adult services. It is always good to think about what you want out of your adult life as early as possible. This is commonly called **transition** ⓘ. This guide has been divided into two sections. The first section talks about what you can expect at different stages of the transition process to adult services. The second section focuses on different aspects of your life that you may want to plan for as an adult. You are very much at the centre of it all.



# Introduction

This guide is for any young person with a life-threatening condition who is thinking about their future as an adult and wanting to consider their options and plan ahead in terms of education, employment and living arrangements, as well as what's important to them in other areas of their life. It aims to help young people make sure that the care and support they need is available so that they can get on with living.

Throughout this guide we have signposted you to further information online and provided explanations of more technical words. Links to further information are highlighted in blue and underlined. By clicking on these links you will be taken to other websites. Links to more detailed explanations are highlighted in colour with an **i** next to it. By clicking on this link a pop up box will open up.

It's important to remember that everyone's transition will be unique. Not only will it depend on your hopes and aspirations, it will also depend on what services and support organisations are in your area and available to you. This guide is therefore quite general and it's important for you to ask those professionals you have a good relationship with about your options.

There are significant differences in health and social care policy across the four nations of the UK and this guide is focused predominantly in that of England. However, much of the advice is the same to everyone, regardless of where you live.

By clicking on the relevant sections of the guide you will:

- get information about making the transition to adult services
- learn more about different options that may be available
- hear from other young adults who have had positive experiences of transition.

We hope that this guide will help you start to think about and plan for your future as an adult.



**Josh's advice to those making the move to adult services is to "love life and live it – it is very precious".**

# Section 1: Stages of transition

You have no doubt already made transitions in your life such as starting school and moving on to secondary school. This guide is about the transition from children's services to adult services and beginning to live your life as an adult.

Although this may feel daunting, knowing what to expect and getting involved in the transition process will help you to think about what matters most to you and enable you to get the most out of adult services and achieve what's important to you.

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**Did you know?** Together for Short Lives has written a guide to transition for professionals called *Stepping Up – A guide to enabling a good transition to adulthood for young people with life-limiting and life-threatening conditions*. This guide sets standards and goals for the professionals who will be supporting you. We have included these standards in the 'What to expect' sections so you can see exactly what professionals should be providing.

# Get ready

The transition process should start when you are about 14 years old. You may be invited to have a transition assessment – the first in a series of discussions you’ll have with professionals to start thinking about your plans for when you are older. It is often the people you know at school, perhaps the Special Educational Needs Co-ordinator (SENCO), who will arrange the assessment and it is important that you are involved from the start and are given information in a way that you understand.

Special Educational Needs and Disability (SEND) reforms began in England in 2014 and stated that all young people with additional needs in education up to age 25 should have support in school to help them. Education, Health and Care (EHC) plans were introduced and will replace SEN statements by 2018.

The professionals around you should help you to think about what you may want to do and your parents/carers should be included in these discussions if you want them to be.

Once everyone has had a chance to learn about what you want to do, people will work together to develop a package of support to make it happen. In some areas there are people that may act as your key worker. Their job is to ensure that services come together on your behalf and to ensure that things that are agreed in your transition plan actually happen. In other areas, there may not be one person carrying out this role but a team of professionals.



### What to expect

#### Standard 1, *Stepping Up* (2015)

“Every young person, from 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.”

### What happens

From the age of 14 years you should expect someone to start discussions with you about making the move to adult services and your plans for the future. It is likely to be someone who knows you well, perhaps from school. These conversations should happen in a place and at a time that is suitable for you and your family. This shouldn't be a one-off meeting but a series of conversations to talk about what you would like to do when you leave school and what support you would like to help develop your independence. There should be a meeting where all the agencies that provide support and care for you, discuss what needs to be put in place. Plans should be drawn up to reflect the support needed at different times, such as when you are unwell and times when your health is stable.

It can take a long time to organise the services that will support you, so remember to think about your longer term goals as well as more immediate ones. If you are not sure what you want to do at this stage or are unsure of what is available, ask for more time to find out. Talking to others who are a little older than you may give you a few ideas or visiting websites where you can read case studies or watch films of people explaining what they did.

### Resources and more information

- [Together for Short Lives](#) has information about transition on its website or you can call the Together for Families helpline for free on 0808 8088 100. Together for Short Lives also has a group you can join if you want to get involved with other young people going through transition.
- [Preparing for Adulthood](#) has lots of information and resources to support young people with disabilities get ready for adulthood.
- [The NHS Choices website](#) has information on what should happen as you reach transition.
- Contact a Family supports families with children with any disability. The organisation has developed useful guides for families, including a factsheet called [Preparing for Adulthood](#). Please note that as policy changes, some of the information you read in publications may become out of date so always double check.
- Many local authorities have written their own guides to support young people in their area. Check your own local authority website. An example of a good guide to transition written by a local authority is Hertfordshire's – [Thinking about the future](#).

### Checklist

- ✓ people have begun to ask you about your plans for the future
- ✓ you feel included in discussions about your future care
- ✓ your family have also been involved and know what you want to happen
- ✓ there has been a **i** multi-agency team meeting to discuss your needs and wishes.



# Get set

Once you have had your initial transition assessment, you will spend the next three to four years continuing to discuss your plans and reviewing whether these have changed at all. You should have at least one review meeting a year. Remember, at each meeting or appointment you should ask what is going to happen as it is really important that you feel in control and aware of any changes that may take place. Also remember that it may take time to organise the services so do discuss your longer term goals at these review meetings too.

It is also important to know that you are allowed to change your mind. Sometimes we learn about the things we don't want by trying them first.

Professionals from children's and adult services should be talking to each other to ensure that their agencies and organisations are working together to meet your needs.

In England the legal age you become an adult is 18 years, in other countries of the UK this varies. However, services apply different age criteria which can be confusing. Wherever you live, by the age of 18 years you should have a transition plan in place.

During this time your legal status as a decision-maker will change and you will be encouraged to take a more active role in making your own decisions. The Care Act introduced in England from April 2015 entitles carers and the people they care for to an **assessment of their needs**  regardless of their income and finances or their level of need. It is important that you and your family are aware of how the **Mental Capacity Act** affects you. The new way that decisions about your care are made once you are an adult is often referred to as a **'person-centred'**  approach where the emphasis moves away from your parents/carers making decisions in your best interests to you making them for yourself. This could feel quite strange for you and your parents and you may need to discuss this change quite openly with your parents – perhaps exploring areas of your life where you would like to take more responsibility. You are likely to still be supported by your family but you'll be asked for your views more and more. You should be supported to take on more self-management of your condition so that you are more confident about things like managing your medications or talking to your doctor. As well as support being available to you, make sure that your parents are supported to take a step back from managing your care themselves.



**“All throughout my illness, and my life in general, the one thing I've always wanted is to be listened to. This is extremely important. I have very little control in my life, being dependent on others for almost everything. The only bit of control I have is my opinion and my ability to make decisions.”**

Lucy

### What to expect

Together for Short Lives believes that the professionals supporting you should be working to meet three standards during this phase.

#### Standard 2, *Stepping Up* (2015)

**“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.”**

### What happens

During this time, you and your parents should be helped to make the shift from family-centred to young person-centred care. You should feel supported to consider future plans and have ongoing meetings with professionals to assess your needs. To help make sure there is no break in your care when you move to adult services, you should have a **key worker**  or transition coordinator to help communicate with the different agencies responsible for your care and support. They will help you identify which adult services can best meet your needs. This should focus on helping you to achieve your aspirations in life, not just assessing your basic daily care needs.

### Checklist

- ✓ you have a plan in place to support your transition
- ✓ a key worker is working with you and your family to ensure that your needs will be met
- ✓ you know what adult services are available to support you
- ✓ you are given more responsibility to make decisions for yourself.

#### Standard 3, *Stepping Up* (2015)

**“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 3 is all about planning how you want to be supported should your health deteriorate and ensuring that the right care and support is in place to provide palliative care. Of course, no-one knows when this will happen but it is important that you have talked to people around you about what you want at this time.

### What happens

It is important that you have discussed what may happen should your health deteriorate with health professionals who know you well. In addition to having a transition plan for your move to adult services, you should also

have an end of life plan. These are sometimes called an [Advance Care Plan](#), or you may know them as Emergency Healthcare or Personal Resuscitation Plans. If you have accessed breaks at a hospice, the staff there can talk through some of the choices and decisions to be made with you and your family. Although difficult to think about, having an end of life plan will help ensure that you are supported to have choice about your end of life care and what happens after your death. It can be a huge relief to have all of this discussed in the open and agreed with your family and friends and care team.

Your family and other carers should feel supported, informed and involved in the development of your end of life plan and should be supported according to their individual needs for as long as they need it. If you have brothers or sisters, they should also be included in any decision making and have the support that they need.

If you are someone who is active online and uses social media, have you thought about creating a digital legacy? [Dead Social](#) is one organisation that has developed resources to help people organise what happens to their online presence after their death.

### Checklist

- ✓ you have an end of life care plan in place that outlines how and where you would prefer to die
- ✓ you have discussed your wishes for your death and funeral with those who are closest to you
- ✓ you feel assured that those around you will be appropriately supported at that time.

### Resources and more information

- The National Institute for Health and Care Excellence (NICE) has published guidelines on the [Transition to adult services](#).
- Together for Short Lives spoke to young people about their experiences of talking about dying and produced a booklet called [Difficult Conversations](#) to help professionals support you more confidently.
- For help in making a Living Will and information about Lasting Powers of Attorney, visit [My Decisions website](#).
- Dead Social has developed an accessible resource *Five steps to sort out your digital legacy* in [English](#) and [Welsh](#).



#### Standard 4, *Stepping Up* (2015)

**“Children’s and adult services are actively working together to enable a smooth transition.”**

### What happens

Moving to adult services will mean changes and things will be different. Remember – change can be a good thing. During this time, you should feel that people from children’s and adult services are working together to provide an overlap of care planning and provision. For example, there may be joint clinics where both children’s and adult clinicians see you together, or your support may come from both children’s specialist nurses and adult specialist nurses. Professionals from all agencies should be involved in planning for your specific requirements and wishes. Use opportunities that arise to ask questions. Make a note of questions that you think of to ask professionals when you meet with them.

It is likely that your plans for the future will change as you get older. It is therefore important that you have ongoing reviews and update your transition plan at least once a year.

### Checklist

- ✓ you have been introduced to people from adult services who may be involved in your future care and have visited services that you may use as an adult such as adult clinics and adult hospices
- ✓ you know what to expect from adult services and have had a chance to ask questions about what may be available to you in your area
- ✓ all aspects of your life as an adult have been discussed and you feel confident that you can live the life that you want.



# Go

When you reach 18 years old you are legally an adult and the expectation is that you will start to receive support from adult health and social care services. With good transition planning from 14 years old, you should have been told about the differences to expect within these adult services and you should have been given the opportunity to meet some of the people from the new adult teams.

There is often some flexibility about when you are actually transferred to adult services, for example if you become unwell, your transfer may be delayed until you are feeling stronger.

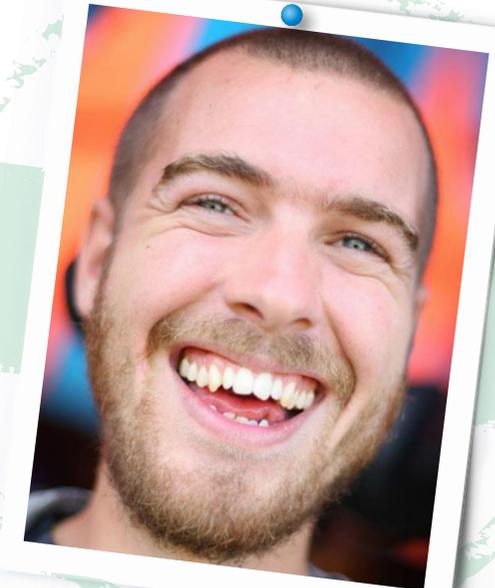
Some young adults may be living independently and managing day to day affairs by themselves, some may be at college or university and some may be living with their parents. What's important is that you are being supported to live as independently as you wish and achieve what is important to you.

It's important to remember that the mental capacity act applies from the age of 16 years and there is an expectation for you to be in control of your plans from 16 years too.

## What to expect

### Standard 5, *Stepping Up* (2015)

**“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 being met in to the future.”**



**“Adjusting to life with personal assistants was a huge leap.” Sam**

### What happens

As you settle into adult life, all the different agencies providing care and support should be working together. You may have a key worker or a transition coordinator to make sure that this is successful.

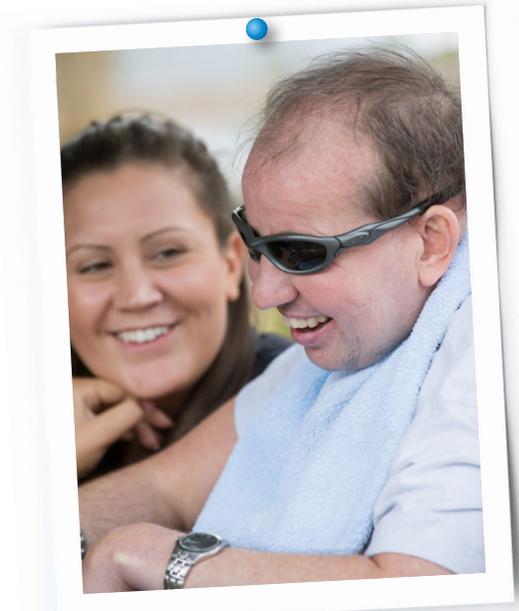
The services you use should feel appropriate for you and your care plan and end of life plan should be reviewed regularly to make sure that they continue to meet your needs and wishes.

Adult healthcare is organised differently to children's services. There is no equivalent of a 'paediatrician', so you should develop a relationship with your GP and other community nursing staff you are in contact with. It is likely that you will have a specialist consultant and that they will provide a clinical overview of your condition. They should also organise clinical appointments or admissions to hospital for you. However, you may have more than one consultant as in adult services they specialise in particular conditions. It is important that a care approach that addresses all your needs is in place. Ask a member of your care team – from the community or hospice service to help coordinate this. Visit the [healthcare section](#) in the Aspects of transition part of this guide for more information on what to expect.

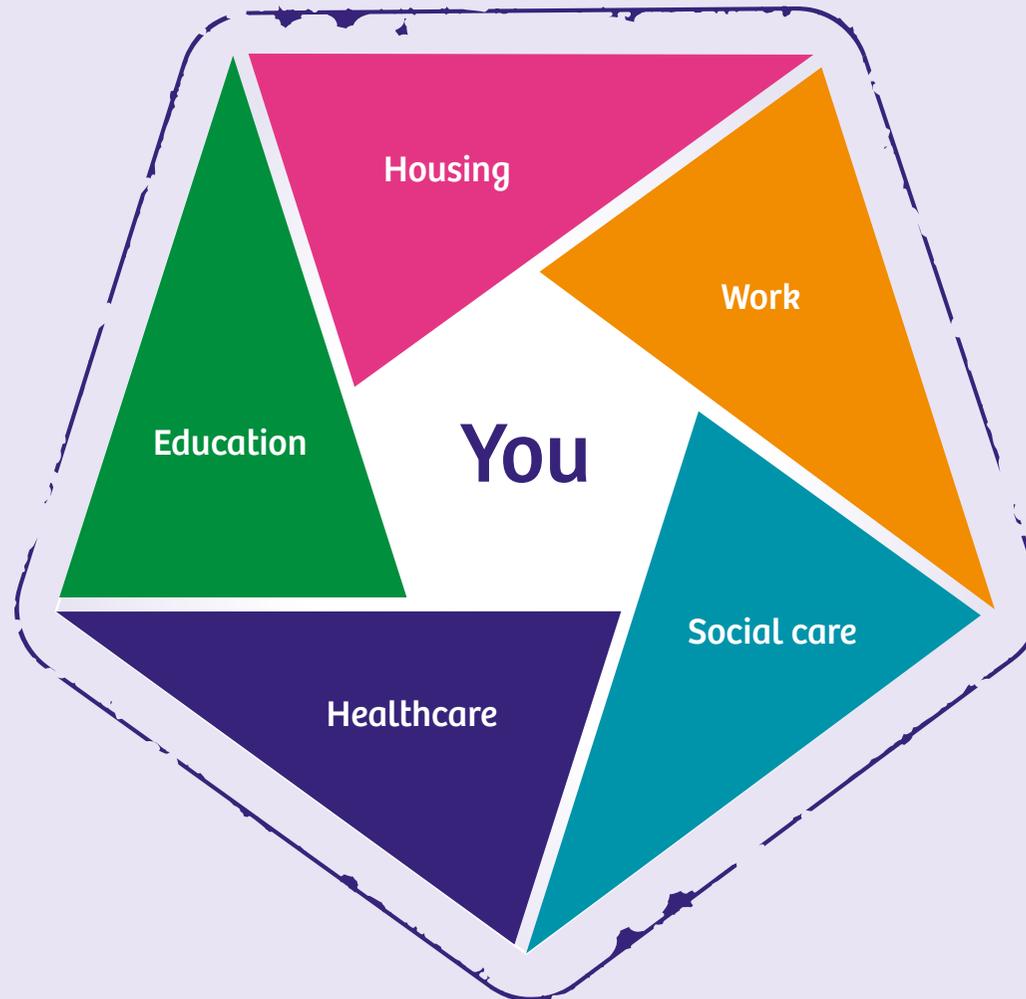
Even once you are settled into life as an adult, your parents should remain included in discussions if you want them to be. Do not assume that people you come into contact with know if you want your parents to remain included – you may need to point this out to them.

### Checklist

- ✓ you feel supported to live how and where you wish
- ✓ you have the appropriate healthcare in place to allow you to live as independently as you wish
- ✓ you know what to expect should you be admitted to hospital as an adult and are prepared for this
- ✓ your care plans are regularly reviewed.



# Section 2: Aspects of transition



# Healthcare

Having a good transition plan in place should mean that you are well prepared when you begin to access adult health services. The plan will enable those responsible for your healthcare to be aware of your specific needs and to be ready to support you. If you have been at the centre of this planning and have had opportunities to ask questions along the way, you will have a good idea of what to expect.

Make sure that your children's care team are involving their counterparts from adult services in any care plans and, if possible, ask to meet healthcare staff from adult services when you are in good health so that you can get to know each other. A [shared care](#)  approach can support successful transitions.

If you are admitted to hospital, it may be that you are placed on an adult ward from the age of 16 years. The environment in adult wards and clinics in hospital can be quite different to what you are used to in paediatrics, so ask your care team to arrange a visit to your local hospital so you can visit adult outpatient clinics and wards. Take the opportunity to ask any questions you may have so you are well prepared should you need to spend time in hospital. There is a growing awareness of the need to adapt adult settings to make them more appropriate for young people and care professionals from adult services are becoming increasingly aware of the need to develop their communication and clinical skills so that they are better able to support young people in their care.

In the [resources section](#) you will find links to tools that can support an effective transfer from children's to adult health services. The NHS Ready, Steady, Go programme has developed a series of checklists for you to complete at each stage of your transfer from children's to adult health services. A 'Health Passport' or '[Care Transfer Document](#)' enables you to record key information about you as a person, your routines, clinical information and the contact details of those involved in your care. Having this written down means that you don't have to repeat all the details every time you meet someone new. It also ensures that people who may have just met you quickly learn what's important for you.



**“It's important to have a certain amount of independence in your own healthcare but also to have the right people around you for those times you need extra help. Moving to adult services had its bumps but, hey, I'm an adult now and this is where I belong.” Hannah**

### GPs and District Nursing (Primary Care)

Everyone's relationship with their GP is different. Often for children and young people with long term conditions, their care is mainly provided by paediatricians and specialist children's teams, so you may not see a GP very often or know the team at the GP practice. GPs should be kept up-to-date by specialist teams' letters about hospital admissions or clinic visits.

It is a good idea to get to know a GP at your GP practice as you approach transition. GPs are experts in navigating local services and [referral pathways](#)  and can therefore play a key role in linking with other adult health and social care providers to make sure your care is joined up. GPs can also provide valuable support to you and your family.

It is important that your GP is included in any assessments so they can keep an overarching view of your circumstances. If you need a lot of nursing support, your GP may advise you to have an assessment for NHS continuing healthcare (adults) or NHS continuing care (children) to help you with healthcare needs. In England, the NHS can arrange care for you or you can choose to receive funding for your care as a direct payment, known as a [personal health budget](#).

Your GP can also provide you with the confidential care you are entitled to as an adult, independently from your parents/carers. GP practice teams provide a wide range of services. Practice nurses for example provide sexual health advice and are often involved in long term condition management. Increasingly GP practices play a role in caring for patients who have had cancer. Many GP practices have close links with adult palliative care teams and district nursing teams.

There is a lot of change happening in general practice at the moment. Lots of GP consultations now take place on the phone. You may find that your GP is starting to use technology such as email and skype to make contact with patients, and there are electronic systems being developed for repeat prescriptions. This may suit you well but might take some getting used to. It is worth finding out from the practice what systems they have in place.

If you go to college or university or move to a new home, make sure you register with your new local GP practice.

### Community care

You may have been supported by your local community children's nursing team as a child. As you move into adult services, you will have staff from different teams providing the care to enable you to stay at home and this will depend on where you live and how services are delivered in your area. Adult district nursing teams are sometimes based at your GP surgery and provide care to adults, often visiting at home to carry out particular nursing procedures. However, their support is usually only provided on a short-term basis. You may be supported by staff from other places too – perhaps from a specialist nurse or community care staff from the local adult hospice.

You will need a package of care tailored to your particular requirements and healthcare staff will need to work closely together to ensure that you are able to remain as healthy as possible while living at home. It is therefore really important that planning begins as early as possible. Clinicians and nurses that have supported you throughout your childhood years and know you well will need to plan alongside those in adult services to enable a seamless transition from children's to adult care. The transition planning process requires a significant handover period between children's and adult services. During this time those working in adult services will become aware of your individual healthcare needs and be able to draw up a plan on how best to meet your ongoing health needs within adult services.

If you have a personal health budget, you may have more choice in how your healthcare is delivered. You may also be able to purchase other services that would be beneficial to you such as hydrotherapy sessions.

### Emergency care

Alongside any Advance Care Plan written while you were supported by children's services, you may have developed an emergency care plan. This contains very similar information but is directed to those who work in emergency services. As you make the transition to adult services, this plan should also be reviewed and adapted for appropriate adult services. Having an emergency care plan in place will ensure that you receive the appropriate care in an emergency situation and avoid any inappropriate or unwanted interventions. This is particularly important if your existing emergency care plan was originally approved by your parents. If you do not already have an emergency care plan, then you should work with your care team in adult services to develop one. Your GP may be able to help you with this too.

Check with your GP to see if your area has an electronic system where you can put special notes about the care you require. This system will enable key information to reach a range of out-of-hours services with your consent. Services such as the ambulance service and A&E Departments will be able to access your key contacts, care plans and see your preferences for place of care.

### Palliative care

Palliative care is holistic care that is provided to people who have a condition that is likely to shorten their life expectancy. Palliative care can be provided in your home, in hospital or in a hospice. It includes not only the healthcare which helps to manage your symptoms and pain, but also social, emotional and spiritual support for you and your whole family. District nurses and GPs have extensive knowledge of adult palliative care and when more specialist input is required to support you, they should discuss how best to meet your individual needs.

You may have been supported by a children's hospice that allowed you to enjoy a [short break](#)  and give your parents to take a break too. You may have enjoyed the opportunity to have a break from your parents and perhaps mix with peers with similar experiences and interests. Adult hospices can feel very different to children's hospices because there will be larger numbers of people using them and many of their service users will be older people who are at the end of life. However, many adult hospices are now beginning to adapt their services for young people and to think about providing special day facilities or other forms of support for young people.

They will be able to provide expert medical and nursing support, emotional support and a range of therapies. In some areas there are dedicated young adult units and if you feel you would benefit from receiving support from them, speak to your GP about hospices in your area and discuss whether a visit would be beneficial to provide an opportunity for you to meet staff and discuss potential support they may be able to offer you.

If your parents are your main carers and you live in England, they are entitled to have a [Carer's Assessment](#) to determine whether they would benefit from additional support. These assessments are arranged through your local social service team and if you are not in contact with them already, speak to your GP who should be able to make a referral.

### Resources and more information

- The [Ready, Steady, Go](#) programme's website has some useful information and tools including a series of downloadable checklists for each stage of transition.
- Health passports were introduced to support the smooth admission to hospital for those with learning difficulties or for those unable to speak at the time of admission. Many areas have adopted this tool so do ask locally if your hospital uses them. Here is an [example of one developed for use by the NHS](#).
- Together for Short Lives worked with a group of young people called Route 66 in Wales to develop a [Care Transfer Document](#) which you can carry with you when you go to hospital to share your particular care needs.

- All About Me documents are also a form of health passports and a good example can be found on the [Foundation for People with Learning Disabilities' website](#). You can download an example of an *All About Me* document that has been developed by a Diana Nursing Team in Salford from the [Council for Disabled Children's website](#).
- Many localities have developed guidance and tools to support conversations about end of life planning. They are referred to by different terms but all have the objective of ensuring that the appropriate care is given to you should your health suddenly deteriorate. Some may be called [wishes documents](#) or [Advance Care Plan](#)).
- Together for Short Lives and the National Council for Palliative Care developed a resource after speaking to a number of young people about their experiences of having [difficult conversations](#) with adults about their end of life wishes.



# Social care

Many social services teams within local authorities now have a transition team in place to support young people move from children's to adult social care. They are responsible for ensuring that you are able to live as independently as you wish and work with other agencies to provide the support that you and your family have identified during conversations with your multi-agency team.

Planning for your transition in England should have involved people from children's and adult social care so they should be aware of what has been agreed within your transition and [Education and Health Care \(EHC\) plans](#) <sup>i</sup>. As an adult, it's important that you have opportunities to make new friends and to try new experiences. Do ask about places or groups it may be appropriate for you to visit or join as talking to others may help prevent you feeling isolated.

## Short breaks

As a child you may well have experienced regular [short breaks](#) <sup>i</sup>, where you had an allocated number of days or nights away from home. This time is referred to as a short break or respite and allows those caring for you to have a break from their caring responsibilities as well as offering you new experiences. You may have enjoyed such short breaks at your local children's hospice or with another charity provider.

As you turn 18 years old your carers – including siblings younger than 18 years that may provide support for you – are entitled to a [carer's or young carer's assessment](#).

It is really important that if you are making the transition from continuing care (child) to continuing healthcare (adults) and have had a [Continuing Health Assessment](#) <sup>i</sup>, adult health services are actively involved as early as possible as different criteria are applied. If you have a personal health budget, you may choose to purchase short breaks yourself.



**“I employ six female personal assistants to provide support around the clock. They support my personal, social and domestic activities. I hire them myself and am their boss. Finding good, dedicated personal assistants can be difficult and stressful. I normally go through my local Job Centre and they match people already on their system with what I want and need.”** Leah

However, residential short break care for adults, and particularly those with complex health conditions, is currently quite limited and varies widely around the country. Some adult hospices are developing new services, such as day care facilities and a small number may be able to offer short break care for young adults. There may also be private nursing homes that can accommodate a short break stay and organisations that can provide a short stay in a family's home. Do ask your social care team about provision that may be available to you as each area has different criteria to access support from these providers, should they be available.

An important feature of short breaks is being able to mix with others and develop friendships. If you have a personal budget you could think about more creative ways for you and your family to have a break. Maybe a weekend away with a personal assistant? A number of voluntary organisations provide fun holiday opportunities for young people with complex disabilities or life-threatening conditions. If you live in England, check your [Local Offer](#)  for details of these and see the Resources and more information section on this page. If you want to talk through options that may be available to you, each area in England has an impartial [information, advice and support service](#) that you can contact.

### Personal assistants (PAs)

Whether you choose to live at home, in supported housing or independently (in or out of your home area), it is important that you are supported to be as independent as you wish. To enable this to happen, you are likely to need additional support day to day and your assessment should determine how this is best provided. In some areas, your social service team may provide the funding for you to have a personal assistant. Personal assistants

can be employed directly by the local authority to come and spend time with you each day or week, helping you in day to day activities such as getting dressed, bathing and doing housework. However, many areas are now putting the money they would have spent on having their own staff working with you into a personal budget.

While this provides you with more say over who cares for you, it does bring some additional work if you are managing your personal budget yourself. Most local authorities have an organisation that can manage all of the employee elements of having a PA. Check locally to see what's available for you.

There is no requirement for personal assistants to have any specific qualification although it is helpful if they have an NVQ Level 3 Diploma in Health and Social Care, as this demonstrates competence to deliver a quality standard of care. However, they may need to gain new skills to meet your specific requirements. There is training available to ensure that your PA has the suitable skills to properly support you – details of some providers can be found in the Resources and more information section on this page.

### Benefits

Your parents or carers may have claimed benefits on your behalf as a child. From the September after your 16th birthday these will only continue if you are in full-time education or on an approved training course. Once you are 16 years old, you may be able to claim certain benefits in your own right. However, you should be aware that this could have an impact on other benefits your family may be receiving.

Personal Independence Payment (PIP) is the new benefit that has replaced Disability Living Allowance (DLA) for adults (aged 16-64) with a disability. As with Disability Living Allowance (DLA), PIP is designed to help you meet some of the extra costs you may have because of a long-term health condition or disability.

### Resources and more information

- [Preparing for adulthood](#) provides knowledge and support to young people, so that young people with Special Educational Needs (SEN) and disabilities achieve paid work, independent living, good health and community inclusion as they move into adulthood. The website has a wealth of information, resources and videos.
- [SENDirect](#) hosts a wealth of information, support and services that can help you find the right support.
- Information on how your benefits might be affected is available from a specialist benefits advisor. Further details can be found from the [Citizens Advice Bureau](#) or at [Benefit Answers](#).
- Information on how the [Personal Independence Payment](#) is calculated.
- [Skills for Care](#) work with employers across England to make sure their people have the right skills and values to deliver high quality care. Information about training for personal assistants can be found on its website.

# Education

There are various choices available to you post 16 and you may 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 you are employed, self-employed or volunteering for more than 20 hours a week.

## Funding

Some young people may require additional funding to attend college. This funding will need to be applied for through your Local Authority Post-16 Student Placement Panel. Funding decisions will be made based upon your agreed 14-25 Transition Plan and your Education, Health and Care Plan (EHC). During 2016, Learning Difficulty Assessments (LDA) will be phased out and replaced by EHC plans. Even if you do not have an EHC plan, you should still expect colleges to make reasonable adjustments to ensure you can access the education you want.

You may be able to apply for funding for post-16 transport to get to your education provider although the application will need to be made every year. In many cases it will be assumed that you will use public transport so do discuss this as part of your planning discussions. There may be some training available to support you access public transport independently.

## Full time education

### Staying at school

You may benefit from staying in school after Year 11. A number of mainstream and special schools have post-16 departments and if this is something you are interested in, make sure it is thoroughly investigated as part of your transition or EHC planning.



**Ben has been to visit the local college and hopes to enrol there full time. As part of his transition he will have a work placement three days a week to undertake a farm management course.**

#### Going to a local college

Further education (FE) colleges generally offer a wide range of vocational and academic courses to meet the needs of students at all levels. They provide support for students with additional needs. This can include specialist teaching support, personal helpers, lifts/ramps or specialist equipment.

Many students with additional support requirements will attend mainstream courses with extra support provided, however you may choose courses better designed to support students with disabilities – for example, courses focusing on developing independent living skills, social skills and education skills. They may also include opportunities to try work-based learning opportunities such as work experience with support, and access to activities in the local area.

#### Studying in a different area

If there is no suitable provision in your local area, it may be that your local authority will provide funding for you to attend a college elsewhere. It may be that there is a general FE college that is outside of your area that can offer the course that you are interested in. There are independent specialist colleges that are available for those who have more complex needs and are unable to study in a mainstream college. For more information on out of county provision, visit the [National Association of Specialist Colleges \(NATSPEC\)](#) website.

### Higher education

For some young people higher education is the next step on from further education. When studying at university or college, you will work towards one of a range of qualifications, such as a degree or a Diploma/Certificate of Higher Education. Young people can go into higher education at any age but most people enter when they are around 18 years old. There's a lot to consider if you do plan to go into higher education, and as a disabled student you will need to think about:

- where to study
- the support you need whilst studying
- support with day-to-day living
- [money and funding](#) 

In England there are two main funding bodies:

#### Education Funding Agency (EFA)

The EFA funds learners between 16 and 19 years old or up to the age of 25 if the learner has a Section 139a Learning Disability Assessment (LDA) or Education, Health and Care (EHC) plan. If you have an EHC plan then your funding will come through the EFA and your local authority.

#### Skills Funding Agency (SFA)

The SFA funds colleges and training providers to offer further education to adult learners aged 19 and over. This includes adults under 25 without an EHC plan or LDA, who self-declare a learning difficulty or disability, and those over 25 with an identified support need.

Colleges and training providers must follow the funding guidelines of these agencies and make sure they are meeting the needs of disabled learners.

### Part time education

Wherever you live, local colleges and learning providers are likely to offer part-time courses too so do enquire about this option if this is something that appeals to you.

### Resources and more information

- Disability Rights UK have produced [a range of useful factsheets](#) and guides to support you to access the education you want.
- Preparing for Adulthood has developed a [toolkit](#) to support the transfer from Learning Difficulty Assessments to Education, Health and Care Plans.
- The Transition Information Network [website](#) hosts information and links to resources to support making transitions in education.
- The Contact a Family [website](#) has information and advice on post-16 education in England. They also have an advice line for England, Wales, Northern Ireland and Scotland on 0808 808 3555.
- You can find out more about accessing Higher Education at [UCAS](#) and [Directgov](#).

# Work

As you move into adulthood you may want to enter the world of work and earn an income or find other ways to make a useful contribution such as through volunteering with a charity or mentoring other young people. If you feel that you need to develop more confidence before applying for positions, there are a range of courses at colleges and work-based learning providers who can offer opportunities to develop work and vocational skills.

You can also get help from the Disability Employment Adviser (DEA) at the Job Centre or Jobcentre Plus. The DEA can provide specialist support to help disabled people find and keep work. Voluntary organisations, such as [Scope](#) and [Mencap](#), also organise work programmes to support people to find and keep a job. There are two government schemes that may help you find suitable work: [Access to Work](#) and [Work Choice](#) (excluding Northern Ireland).

Whatever your aspirations are, they need to be discussed from an early age and included in your transition plan to ensure that the necessary support from health and social care is available to allow you to work as you choose.

## Supported employment

Young people with disabilities have been helped to secure a job through [Supported Employment](#) . Supported Employment uses a partnership strategy to enable those that receive adult social care to remain employed for as long as they wish. Arrangements may vary depending on where you live so do check locally. Although you may require more flexibility to allow time off for appointments or if you become unwell; your employment terms and conditions of work should be the same as everyone else, including pay at the contracted going rate and equal employee opportunities for career advancement.

**“I never dreamt I could be so successful. For the first time in my life, I’m treated like everyone else in society. No-one judges me here, they recognise my talents.”**  
Intern at National Grid 2015

[The British Association for Supported Employment \(BASE\)](#) provides a range of support for both young people and employers about being matched for employment, training, in-work support and career development. Their website has a list of agencies that can be contacted locally for support.

### Supported internships

Supported internships are a structured study programme based primarily within an employing organisation. They enable young people aged 16 to 24 with a statement of SEN, a Learning Difficulty Assessment or an Education, Health and Care plan to achieve sustainable paid employment by equipping them with the skills they need for work, through learning in the workplace. Supported internships are unpaid and last for a minimum of six months. Wherever possible, they support the young person to move into paid employment at the end of the programme. Alongside their time with the employer, young people complete a personalised study programme which includes the chance to study for relevant substantial qualifications, if appropriate, and English and maths. For more information on supported internships visit [here](#).

### Work-based learning

Work-based learning may be the route for you if you want to work but still gain a qualification. A wide range of training opportunities are available. Work-based learning caters for all abilities and offers you the opportunity to get all the work skills and qualifications employers demand in the job market.

There are various options available through work-based learning:

#### Foundation Learning

Foundation Learning is available to all young people between the ages of 16 and 18. Foundation Learning offers support to young people who might not be ready for an apprenticeship, further education or employment and can help with basic skills and key skills, vocational skills and your personal development.

#### Traineeships

Traineeships are for young people who want to work, but who need extra help to move into an apprenticeship or a job. Traineeships will give you the opportunity to develop the skills and gain workplace experience that employers ask for.

#### Intermediate Level Apprenticeships (Level 2 and Level 3)

Intermediate Level Apprenticeships lead to Level 2 or 3 qualifications. On Intermediate Level Apprenticeships, employed apprentices will receive a wage of at least the National Minimum Wage rate for apprenticeships.

#### Advanced Level Apprenticeships (Level 3)

Advanced Level Apprenticeships lead to Level 3 qualifications. On Advanced Level Apprenticeships you will be employed and receive a wage of at least the National Minimum Wage rate for apprenticeships that will reflect your skills, experience and ability.



#### Higher Level Apprenticeships (Level 4)

Higher Level Apprenticeships lead towards work-based learning qualifications (including Level 4 qualifications) and, in some cases, a knowledge-based qualification such as a Foundation Degree. The terms of employment for an apprentice may vary according to your particular circumstance so ask your advisor for more information.

### Resources and more information

- [This government website](#) gives tips on looking for a job if you are disabled and outlines how a Job Centre 'Work Coach' can help.
- [Skill](#) is a website for young people providing information and support for those looking to find work or volunteering opportunities.
- Disability Rights UK has produced [a range of useful factsheets](#) on your rights in employment.
- Preparing for Adulthood has a range of information on supported internships and the Access to Work fund on its [website](#).

# Housing

Many young people are quite happy to remain at home as they reach adulthood. However, you may want greater independence and there are a variety of housing options that you may wish to consider. Assistive technology can help you be as independent as you wish, wherever you live.

If you live in England, your [Local Offer](#) 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) and more detailed advice on accommodation and support.

## Buying or renting another property

Getting a foot on the property ladder is a real challenge for most people, regardless of age or ability. However, if you have the resources, this may be one option for you. The important factor is that the property is suitable for your needs.

If you're looking to rent, your local authority may be able to help you find a property that has been adapted and is fully accessible. If you are looking to make your own adaptations in a rented property or in your own home, you may be eligible to receive a Disabled Facilities Grant (DFG) from your local authority to go towards the cost of any necessary changes.



**“With housing it’s so important to think ahead as adaptations take time and money. The original adaptations made to my house are already no good as I’ve needed to start using a larger wheelchair.”** Chris

### Sheltered housing

Sheltered housing schemes are flats or homes which are designed for independent living but have extra facilities to support those with additional needs. They may have a warden who can be called in an emergency or communal facilities to ensure that you have a chance to socialise.

This model of accommodation is well known for older people but there are a growing number of schemes being developed which cater for the needs of younger disabled adults.

### Supported housing in the community

If you are able to be quite independent and only need a limited amount of support to live on your own, it may be that supported housing would suit you.

There are a wide variety of residential units in the community – some are managed by the local authority, others by housing associations, voluntary organisations and charities which run the units to meet particular support needs.

### Shared living schemes

Shared living schemes work by matching you with a carer in the community who can support your care needs. It may be that you live with the ‘shared living’ carer in their own home – either on a long term placement or for a short stay. Alternatively, they may come and live as part of your family, in your own home.

### Resources and more information

- The Housing and Support Alliance [website](#) provides a host of useful information. They also have an advice line on 0300 2010 455 and email service [enquiries@housingandsupport.org.uk](mailto:enquiries@housingandsupport.org.uk).
- The Scope [website](#) hosts a range of information on independent living for disabled people.
- [Disability Rights UK](#) works to create a society where everyone with experience of disability or health conditions can participate equally as full citizens. This area of its website provides additional information on housing.
- This [government website](#) provides information on financial help for housing for disabled people.
- [Ability Housing Association](#) provides housing, care and support services for people who want to live more independently.
- The [Housing Executive website](#) has a dedicated section on housing for disabled people.
- [Housing Options Scotland](#) has the latest news regarding disability housing in Scotland.
- [SAHN](#) is a network of user-led housing and disability organisations.
- [Disability Wales](#) has information on accessible housing registers in Wales.



# You

You must be involved in all the discussions about your future and feel able to speak up when you don't understand something or feel that you are not being properly listened to.

This is not always easy. Some professionals may sound as if they know everything. But no-one knows what you want and need as well as you. There may be times when you feel as if you need some support in order to get your views heard. Someone who acts on your behalf is known as an **advocate**  and they can play an important role in making sure your move to adult services goes smoothly.

It may be that your parents are your advocates. However, as with all teenagers and young adults – there may be things that you don't agree on. Remember that as well as being your advocate, parents continue to have a parenting role to play so do take the time to discuss how they can best carry out both roles.

You may prefer to have an independent advocate and there are schemes around the country that offer this support. There may also be opportunities for you to have a mentor or join a befriending scheme.

## Having control and influence

If you have been kept at the centre of your transition planning process, you should feel as if your voice has been heard and that you have been able to influence decisions being made. One thing that you may find frustrating is not being sure about who is responsible for what. It is important that you are clear on what goals you want to achieve and make sure that you are enabled to meet them. In some parts of the country, you may be able to request that you have a personal budget to spend on support and activities that will best suit you. In England, anyone who has an EHC plan assessment can request a personal budget. You have the right to request a personal budget now if you are entitled to adult social care and in receipt of health support. Find out more about personal budgets by downloading the [Young Person's Guide to Personal Budgets in England](#).



**“There’s a will and there’s a way. I choose the way – my way. We are all superheroes in our own way, each and every one of us.”** Laura

If you are going through the process of having an Education, Health and Care plan you may be entitled to [Independent Support](#).

Your parents and carers may be supported by an organisation specific to your condition and, as you get older, you may want to join their forums and groups in your own right. These can be great ways of getting to know other people who have lived through similar experiences. You can find details of condition specific support organisations on the internet by calling the Together for Families helpline on 0808 8088 100 or the Contact a Family advice line on 0808 808 3555.

### Becoming an adult

Everyone matures at different rates and in different ways. As you get older, you will notice many changes. There are physical changes that take place that are visible to those around you. There are also internal changes that take place that may be less obvious – even to those close to you. Everyone experiences developmental changes as part of the growing up process. It is natural for your interests to change and as you lose interest in some activities, take opportunities to find other hobbies, interests or new social groups.

Whether it's wheelchair football, a youth club (many children's hospices provide these now), faith group or a school group, mixing with others your age can ensure that you keep socially active. This is a real benefit to your emotional health. Having opportunities to talk about how you are feeling is really important and you may value talking to a counsellor or another trusted adult to talk things through in confidence.

If you are looking to join online groups, a quick search on the internet will pull up a list of possibilities. Reputable groups should have systems in place to ensure appropriate membership but always be aware of the potential risks of sharing information with people online. [Get Safe Online](#) provides guidance and advice to ensure that young people are kept safe online.

Your emotional health is as important as your physical health and belonging to a social or sporting group is one way of supporting this aspect of your life. Many young people want to develop relationships, explore their sexuality, love and be loved. All this is perfectly normal and you should be supported to help you enjoy intimacy with a partner if that is what you want.

### Resources and more information

- *Talk about Change* is a film produced in 2008 by young people with life-threatening conditions. Based on in-depth interviews and their own video diaries, it provides an insight into their journey from childhood, through the teenage years into adulthood. To borrow the DVD email [info@togetherforshortlives.org.uk](mailto:info@togetherforshortlives.org.uk).
- The Open University worked in partnership with Together for Short Lives to develop [Talking about sex, sexuality and relationships](#). This guide features real life case studies to show how the law applies in practice, along with the views of young people on the specific challenges they face in developing their sexual identities.
- *The Whole Picture: Exploring disability and sexuality* is a training resource on DVD on the topic of disability and sexuality. Although developed for professionals, it is also of interest to disabled young people and their families. To request a copy email [info@togetherforshortlives.org.uk](mailto:info@togetherforshortlives.org.uk).

# Links to organisations and advice in Scotland, Wales and Northern Ireland

While the principles of what to expect during the transition process are the same wherever you live in the UK, this resource has focused primarily on policy and structures in England. Many of the organisations listed support people in England and Wales. We hope that with additional funding we can develop specific guides for young people with life-threatening conditions in other UK nations.

Meanwhile, here are links to useful information for families living in Northern Ireland and Scotland, developed by Contact a Family.

[Preparing for adult life and transition: information for families – Northern Ireland.](#)

[Preparing for adult life and transition: information for families – Scotland.](#)

### **Moving to Adult Services: What to Expect**

is published by Together for Short Lives in England. Together for Short Lives is a UK wide charity that, together with our members, speaks out for all children and young people who are expected to have short lives. Together with everyone who provides care and support to these children and families we are here to help them have as fulfilling lives as possible and the very best care at the end of life. We can't change the diagnosis, but we can help children and families make the most of their time together.

Throughout this guide we use the term life-threatening but acknowledge that other terms such as life-shortening and life-limiting are often used.

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