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An introduction to… 10 Steps to Transition (Alder Hey)

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https://10stepstransition.org.uk/

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What is it?

- Framework that works with other transition tools
  - RSGH, GUGI
- Particularly useful for complex, multi-specialty cases
- Helps professionals to identify and coordinate care
- Reassurance for YP and families that we are thinking beyond medical needs

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10 Steps transition to adult services: What good looks like

Information for young people and their families

www.10stepstransition.org.uk

What is transition to adult services?

When children become adults it is normal for them to make decisions for themselves and to lead a more independent life. Children's health and care needs also change as they grow up. **Transition to adult services** (Transition) is the name given to the process of moving on from children's to adult services.

Transition is an important journey. The team at Alder Hey Children's Hospital will work with you and your family to ensure that you get the support you need every step of the way. We will ensure that you and your family understand what is happening, feel confident and in control. This leaflet explains what good Transition looks like and what you should expect.

This leaflet is mainly concerned with Transition to Adult Health Services. Some young people with more complex needs also have support from social care and special education. When this happens we will work with these services to co-ordinate the different transitions.

Why do we need transition to adult services?

Transition is important to ensure that services are appropriate for your age and needs. If we didn't have Transition to Adult Services adults would be nursed on the same wards as babies and children. Services that are needed for babies and children would not be available because adults were using them.

What will happen during transition?

Transition is a gradual process. Young people and their families often need guidance and encouragement but you shouldn't feel rushed or unsupported.

We can think of transition a series of ten key steps. Let's look at these steps together.

1. Identifying young people needing transition

Professionals will normally start talking to you and your family about your health needs and Transition to Adult Services around the time of your fourteenth birthday. This will allow plenty of time for gradual planned Transition. Sometimes professionals will write a letter summarising your diagnosis and health needs or we may put this information a Health Information Passport or Advance Care Plan. You should be given a copy of this information, have the opportunity to read it and ask questions. This information should be updated as you progress through Transition.

2. Empowering young people, supporting parents

We will work with you, depending on your age and ability, to help you develop the knowledge and skills you need to keep healthy and well. We will give you the opportunity to talk about how your health needs may impact on your future including employment, independent living, sexuality and relationships. You can also discuss risky behaviours like smoking, alcohol and drugs. You will also have the opportunity to be seen without your parents for part of your clinic appointment.

Some young people with learning disabilities will need help to stay healthy and well, and to make decisions about their care, when they are adults. We will ensure that there is someone available who can support and advocate for these young people.

3. Starting a Transition Plan

We will work in partnership with you and your family to create your personal **Transition Plan**. This will be tailored to your health needs and co-ordinated with other aspects of

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10 Steps Transition Pathway

Transition to adult services for young people with long term conditions

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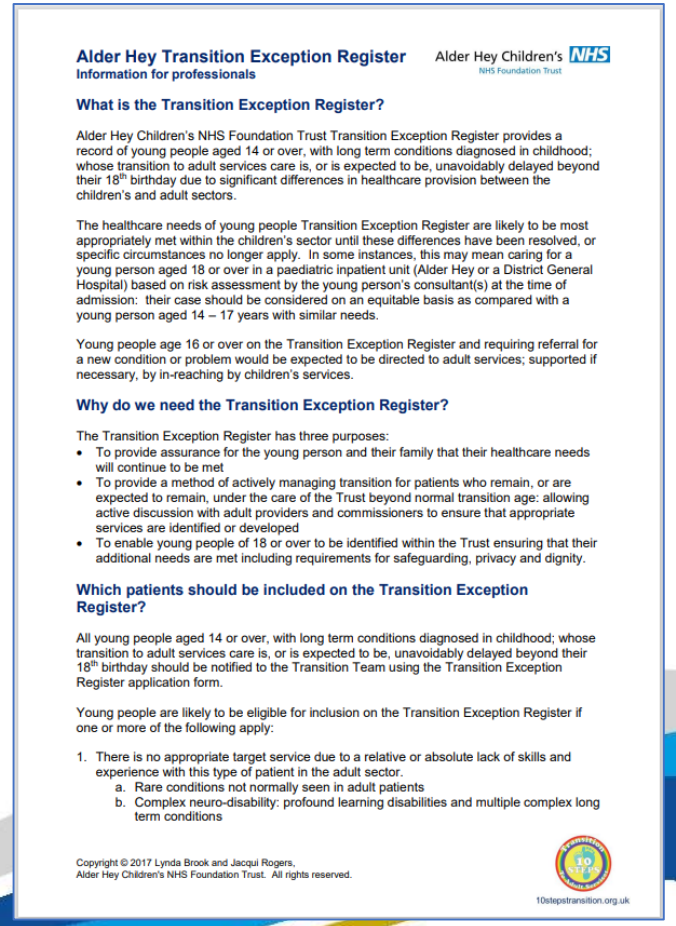
Exception Register

- method of managing transition for patients who remain, or are expected to remain, beyond normal transfer age
- facilitates discussion with adult providers and commissioners to ensure that appropriate services are available
- ensures that additional needs of young people of 18 are met including requirements for safeguarding, privacy and dignity
- assurance that healthcare needs will continue to be met



Alder Hey Transition Exception Register
Information for professionals

Alder Hey Children's NHS Foundation Trust

What is the Transition Exception Register?

Alder Hey Children's NHS Foundation Trust Transition Exception Register provides a record of young people aged 14 or over, with long term conditions diagnosed in childhood; whose transition to adult services care is, or is expected to be, unavoidably delayed beyond their 18th birthday due to significant differences in healthcare provision between the children's and adult sectors.

The healthcare needs of young people Transition Exception Register are likely to be most appropriately met within the children's sector until these differences have been resolved, or specific circumstances no longer apply. In some instances, this may mean caring for a young person aged 18 or over in a paediatric inpatient unit (Alder Hey or a District General Hospital) based on risk assessment by the young person's consultant(s) at the time of admission: their case should be considered on an equitable basis as compared with a young person aged 14 – 17 years with similar needs.

Young people age 16 or over on the Transition Exception Register and requiring referral for a new condition or problem would be expected to be directed to adult services; supported if necessary, by in-reaching by children's services.

Why do we need the Transition Exception Register?

The Transition Exception Register has three purposes:

- To provide assurance for the young person and their family that their healthcare needs will continue to be met
- To provide a method of actively managing transition for patients who remain, or are expected to remain, under the care of the Trust beyond normal transition age: allowing active discussion with adult providers and commissioners to ensure that appropriate services are identified or developed
- To enable young people of 18 or over to be identified within the Trust ensuring that their additional needs are met including requirements for safeguarding, privacy and dignity.

Which patients should be included on the Transition Exception Register?

All young people aged 14 or over, with long term conditions diagnosed in childhood; whose transition to adult services care is, or is expected to be, unavoidably delayed beyond their 18th birthday should be notified to the Transition Team using the Transition Exception Register application form.

Young people are likely to be eligible for inclusion on the Transition Exception Register if one or more of the following apply:

1. There is no appropriate target service due to a relative or absolute lack of skills and experience with this type of patient in the adult sector.
   a. Rare conditions not normally seen in adult patients
   b. Complex neuro-disability: profound learning disabilities and multiple complex long term conditions

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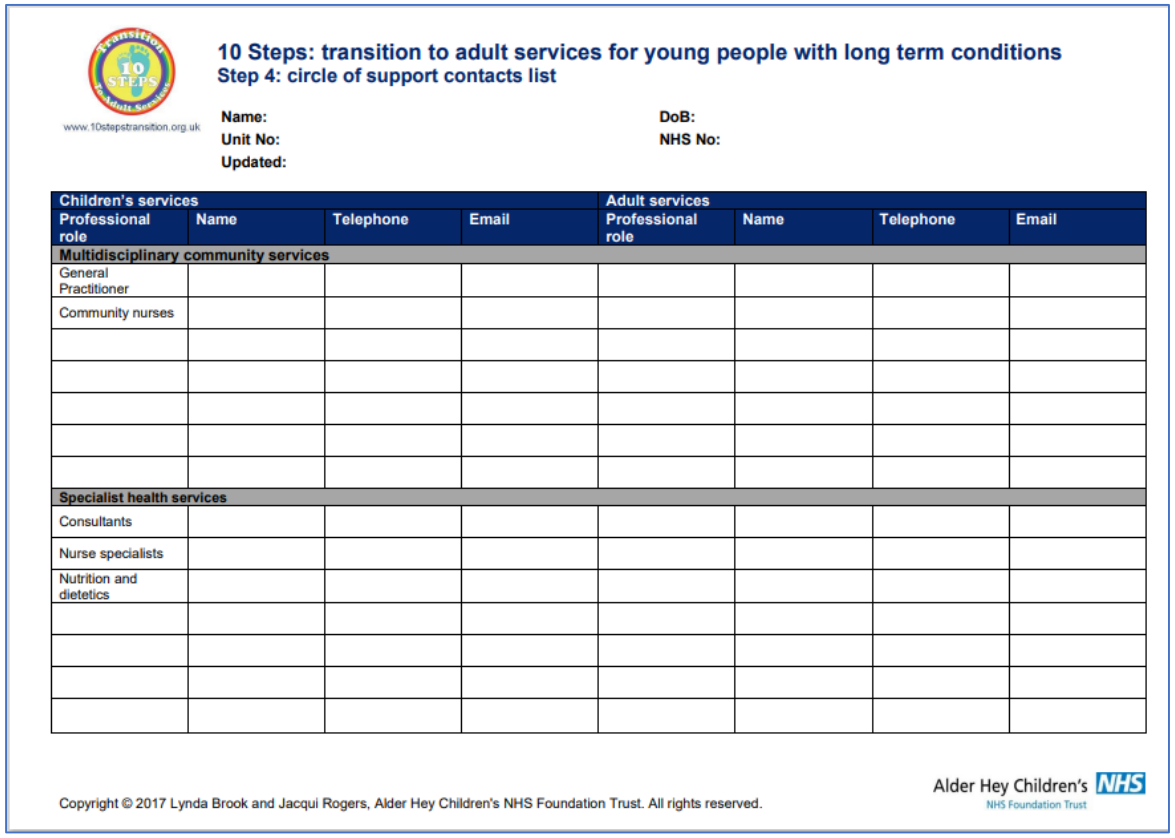
MDT coordination



10 Steps: transition to adult services for young people with long term conditions
Step 4: circle of support contacts list

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Name: DoB:
Unit No: NHS No:
Updated:

Children's services				Adult services			
Professional role	Name	Telephone	Email	Professional role	Name	Telephone	Email
Multidisciplinary community services							
General Practitioner							
Community nurses							
Specialist health services							
Consultants							
Nurse specialists							
Nutrition and dietetics							

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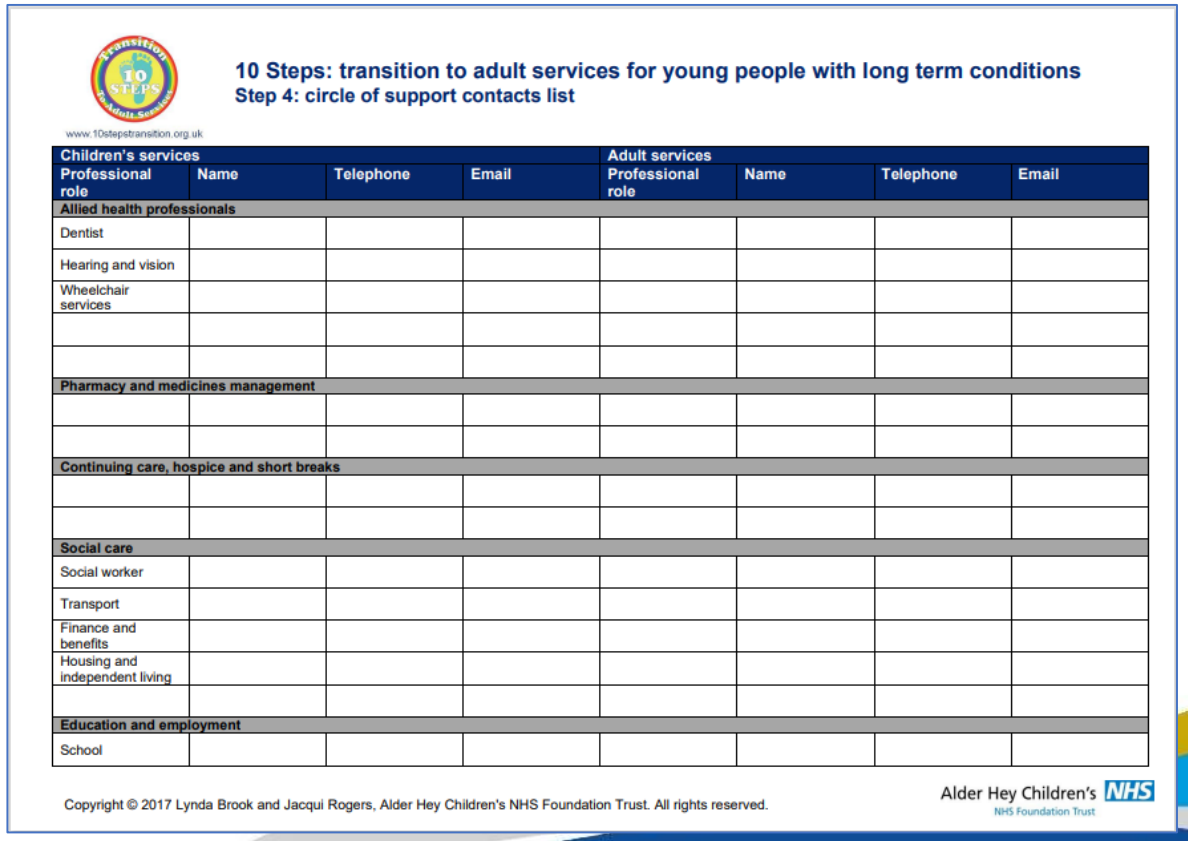

10 Steps: transition to adult services for young people with long term conditions
Step 4: circle of support contacts list

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Children's services				Adult services			
Professional role	Name	Telephone	Email	Professional role	Name	Telephone	Email
Allied health professionals							
Dentist							
Hearing and vision							
Wheelchair services							
Pharmacy and medicines management							
Continuing care, hospice and short breaks							
Social care							
Social worker							
Transport							
Finance and benefits							
Housing and independent living							
Education and employment							
School							

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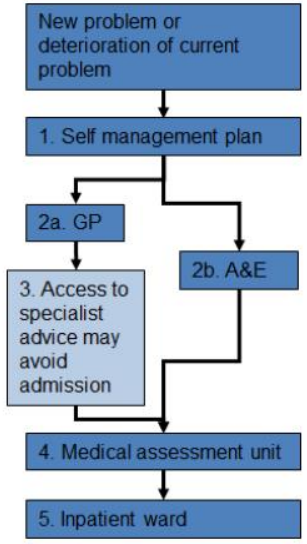
Accessing urgent care

10 Steps: transition to adult services for young people with long term conditions
Step 7: planning your route into urgent care

Name: **DoB:**
Unit Number: **NHS No:**



Stage	Where will this happen?	Who will be involved?	What knowledge and skills will be needed?	How can we ensure the right information and support is available?
1	At home	Parents, carers and #	Physio therapy Management of epilepsy Gastrostomy feeds & care To keep # healthy and well, by administration of all # medications and her feeds.	Training has been delivered previously by staff at Alder Hey hospital. It is possible to access refresher training from the Carer Skills Passport Project at Alder Hey Physiotherapy delivered and techniques shared with family.
2a	At home or at GP practice	GP, parents, carer and #	Understanding of infection-recognising and diagnosing infection and prescribing appropriately Recognise # is becoming unwell and needs to see GP.	Qualified staff will diagnose and prescribe.
2b	A&E	Parents, carers, #, Ambulance crew, doctors and nurses at A&E	Possible Gastrostomy replacement/ Chest infection. Seizure control. Recognise # is unwell and needs to access urgent care, will call an ambulance. A&E will make any diagnosis and prescribe appropriate medications, and admit # if necessary.	All knowledge, skills will be delivered by trained staff.
3	At hospital or home dependent on service	Parents/ Carers/ #/CCNT/ A&E staff/ Physiotherapists/GP	Possible Gastrostomy replacement Change in consumables/ equipment.	All knowledge, skills will be delivered by trained staff
4	N/A	N/A	N/A	N/A
5	Alder Hey based ward-## will be an inpatient	Parents/ Carers/ # /doctors /nurses / Physiotherapists/ LD team	Knowledge of # what # likes and does not like. Possible mi-key replacement. Possible seizure control management. Possible treatment of chest infection Treatment of any other concern #presents with.	All knowledge, skills will be delivered on ward by trained staff.

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An introduction to… Stepping Up (together for short lives)

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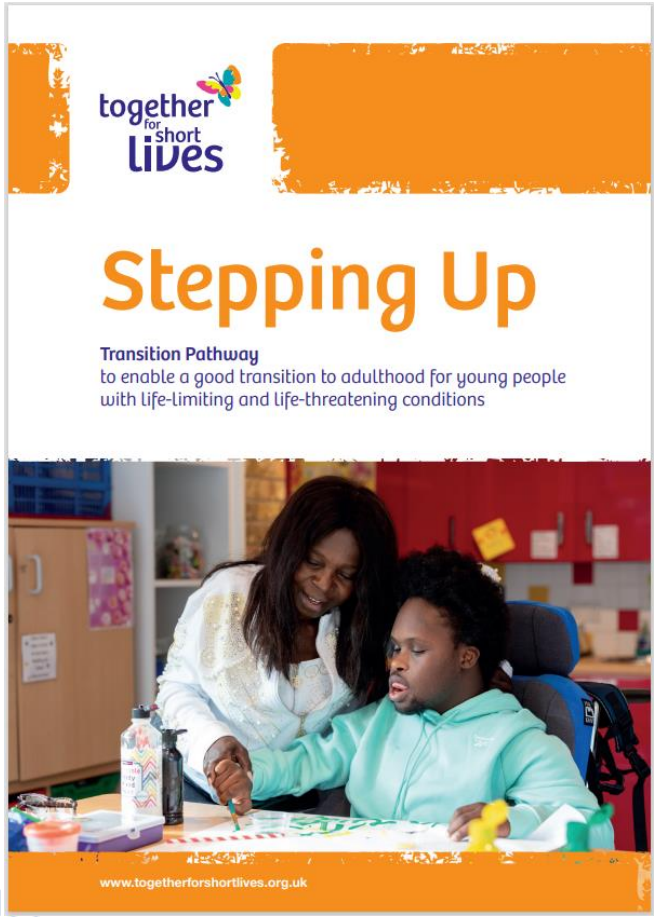
https://www.togetherforshortlives.org.uk/resource/transition-adult-services-pathway/



- Comprehensive guidance
- 5 Standards expected of services each with a number of goals
- Siblings
- Parallel planning takes place for transition to adult services alongside plans for deterioration (Advance Care Plans)
- Good practice examples

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The Three Stages of the Transition Pathway

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.

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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.

There is a version of these standards for young people to use as a checklist to a good transition:
www.togetherforshortlives.org.uk/get-support/supporting-you/family-resources/a-checklist-to-a-good-transition

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Intended to be used by young people and their families but can also be used to guide discussions between professionals, young people and their family members and prompt conversations around transition and advance care planning.

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Name: Date of birth:

Phase 1: Preparing for adulthood – Young person age 14+

You can answer these questions when you have started talking about your plans for the future with teachers and care providers.

We believe:
- Every young person from age 14 should be supported to be at the centre of preparing for approaching adulthood and for the move to adult services.
- Families should be supported to prepare for their changing role.

Goals		Are these goals being met?		
		Yes	No	Partially
A1	I have talked to my parents, teachers and others involved in my care about my plans for the next few years.			
A2	I have a named worker who I trust and who I can talk to about what I want to do.			
A3	I know what to expect as I get older, move on in my education and have support from adult services.			
A4	I know what type of care and support options will be available when I'm older.			
A5	I have discussed what care I may expect if my health gets worse at any time in the next few years.			
A6	I know how to remain involved in matters concerning my transition.			
A7	I am aware of assessments that I may need to have.			
A8	I know what peer support (support from other young people who have experience of transition) and advocacy (support from someone independent from children's or adult services who can represent your interests) is available throughout my transition.			
A9	I have been given information about how funding for my carers may change as I get older.			
A10	My parents are clear about their role in supporting me to make decisions about my future.			

Name: Date of birth:

Phase 3 – Settling into adult services – Young adult age 18+

Support doesn't stop once you've made the transfer to adult services and you should continue to receive the help and information you need to thrive in adulthood.

We believe:
- Every young person should be supported in adult services with a multi-agency team fully engaged in facilitating care and support.
- The young person and their family should be equipped with realistic expectations and knowledge to ensure confidence in their care and support needs being met in the future.

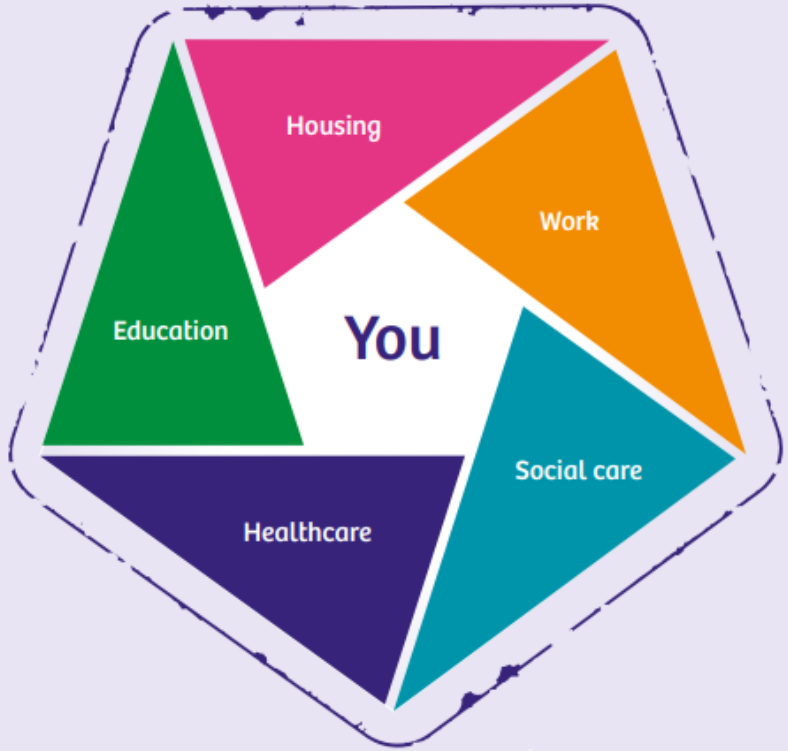
Goals		Are these goals being met?		
		Yes	No	Partially
C1	I feel that the care and support provided by all the agencies is well co-ordinated.			
C2	I am building good relationships with new healthcare professionals from adult services, including my GP.			
C3	I am able to access services that address my needs and that are appropriate for my age and understanding.			
C4	I know where to go for information or who to go to for advice.			
C5	I have access to an advocate, offering independent support and representing my interests if needed.			
C6	I know who my lead doctor is, to take responsibility for me when I attend adult clinics for my condition or am admitted to hospital.			
C7	I am aware of any options available to allow my parents/carers to have respite from their caring role.			
C8	I am given opportunities to socialise with friends and maintain hobbies and other interests.			
C9	I am proactive in ensuring that my care plans are updated and reflect my care needs and wishes.			
C10	My parents are happy with the level of involvement they have in helping me make decisions.			

Moving to adult services: what to expect

Moving to Adult Services: What to Expect
A guide for young people with life-threatening conditions making the transition to adult services

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** ❶.
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.

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