

Information for young people and families

This is a guide to help you and your family understand the process of moving your care from child to adult services (known as transition). It aims to encourage you to start the conversations early with your health care team around what this means for you. This is important because it allows time for you to learn about your health condition, ask any questions and to have any discussions that are needed. This will help you to feel prepared.

At the back of this guide is a notes section where you can write down any questions you have ahead of conversations with your health care team. The Bladder & Bowel UK team are also here to support you and you can contact the helpline for advice and support on your journey. The team of specialist nurses have experience in transition and would be happy to help you.

What is transition?

Transition is the word used in health care to describe the process needed to prepare and plan your move from children's care to adult care. It is recommended that this begins aged eleven to twelve years old. Everyone's transition process will look and feel different, and your health care team will be able to provide you with more information on the process they use to support you on this journey.

This is not a rushed process. In fact, you and everyone involved in your care works together as a team over time. This means there will be lots of discussions about what would be best for you and all plans are made together, with your wishes and feelings a priority. It can take time for your health care team to help you feel fully prepared for the move. You will probably have become very comfortable with the healthcare professionals who have looked after you so far. However, working with them, you should have the time to learn about your condition, your treatments and the choices you can make about your care.



You should also have opportunities to meet and get to know the adult service before you leave the children's service. This will help you to know how things will work when you move to the adult service. It will also give you time to get to know the staff who will be looking after you in the future and to ask any questions, so that you feel comfortable.

Why do I have to move?

Childrens' services are unable to provide some of the care and advise you will need as you get older. From the age of eleven they will start to prepare you to meet professionals from the adult services who will be quite happy to work alongside the children's professionals. They are better able to discuss issues such as travel, education, careers, sex and relationships with you. As you become older you will also likely want to have conversations about your care in a grown-up setting rather than a children's ward or department.

When do I have to transition to adult services?

This decision is made together between you and your health care team when the time is right for you. The discussions around transition usually start when you reach eleven and together, you and your health care team will create a programme that works for you. Your health care team may feel you are ready sooner than you feel you are, and this is alright. This guide helps you to begin thinking and talking about this change and gradually develop your skills and confidence to take charge of your own health care.

Is there a choice where I move to?

Your local Consultant or GP will help you as part of the transition process to look at the different choices available in your area and you should be given the opportunity to visit these so you can decide which you prefer and would suit you and your plans best.



Who can help me get ready?

Your healthcare team will support and advise you by:

- Teaching you more about your illness or condition, which can include any treatments or side effects. By helping you understand this more, you can find it easier to make decisions about your care.
- Providing clinic appointments when you attend without your family for some or all the appointment – this would only happen when you are ready.
- Providing information on who to contact in an emergency, or if you have any questions or concerns, so you know where to get help if needed.
- Having discussions that make it easier for you to understand how your condition or illness links with any career or education plans.
- Signposting you to support networks that are available:
- 1. Mencap transition into adult services
- 2. Council for Disabled Children
- 3. WellChild
- 4. Contact for families with disabled children
- 5. <u>Kidz to Adultz magazine</u>
- 6. Kidz to Adultz exhibitions
- Supporting you to understand the benefits of maintaining a healthy lifestyle, topics covered include exercise, diet, smoking, alcohol and recreational drug use and sexual relationships.

Your parents & carers

The transition process is focused on you, but it is important to remember that your family can still be involved in your care and be able to offer useful advice and support, as they have the experience and understanding of your condition.



It is useful to have discussions with your parents/carers about any questions they may have so that they can continue to support you. It is normal for them to feel worried but discussing their feelings can be helpful to you all as you work through the transition process. Parents and carers can also be very supportive with the practical aspects of your care like arranging prescriptions or appointments or asking questions in clinics whilst you are learning to be independent with this.

What if you're a young person with a learning disability or additional need?

Learning disabilities and additional needs are common and may occur with complex health conditions or without. Often, health professionals tell parents/carers about your condition when you may be too young to understand. When you are older and ready to become more independent, health professionals will work with you to teach you about your health and how to manage your condition.

It can be helpful to include other professionals in your transition such as your learning disability nurse or social worker, some areas have specialist transition social workers.

They can help describe and provide a list of who is looking after you now and who will look after you in the future. This helps you and your team plan how to get there.

The Mental Capacity Act is a law that you need to know about for when you are over 18 years old (and some decisions between 16 and 18).

- This means that where you can make decisions, then people should allow you to do so
- The law also tells professionals how to decide whether you can be supported to make decisions for yourself

Your social worker/learning disability nurse can give you more information about this.

You may wish to create a health passport with your health professionals. This is a form where you and your family can write down what you find difficult and things that help you. This allows doctors and nurses to know the best ways to work with you.



Your GP is an important person in your care. If you have a learning disability, it is important that you and your carers let the GP surgery know that you need to be on their learning disability register. This will entitle you to an annual health review with them. This will give you another opportunity to make sure that you are getting the support with your health that works for you.

Questions that can be helpful to ask and discuss with your health care team

- What is my transition plan, and can I be involved?
- When will we start to work on transition?
- Can you help me understand how my condition will affect my future e.g., education or employment?
- What are the options around my treatment and healthcare?
- What are the possible benefits and/or risks of these?
- Who is there to help me in making decisions?
- When will I move to adult services and what do I need to know before I do?
- Can I choose the adult service I go to, and can I look around?
- What is different about the adult service compared to the children's service?
- Do I get to meet the adult team before I leave children's team?
- Are there other young people who I can talk to who are at the same stage as me?

Further information

Find more information about child bladder and bowel health in our information library at www.bbuk.org.uk. You can also contact the Bladder & Bowel UK confidential helpline (0161 214 4591).

For further advice on bladder and bowel problems speak to your GP or other healthcare professional.



The development of transition within the NHS is evolving, and we intend to keep this guide updated in line with the best practice evidence as and when this is published.

| Use this section to write any questions or notes you would like to share with your health care profession | al: |
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