

I'm transitioning to adult services and

DON'T KNOW WHAT WILL HAPPEN



You may have heard your nurse or doctor talk about transition and not be sure exactly what it means. As a young person you may be becoming more independent and making decisions about your future, and so it is important that this includes your health. Transition is the process of supporting you in understanding your condition, and helping you develop the confidence and skills to manage your condition. A part of this is moving from

services designed for children and young people to services designed for adults, and this usually happens when you are 16-18 years old. This might feel a bit daunting, especially if you have been seeing the same doctors or nurses for a while, but the process of transition shouldn't feel hurried. Your care team will talk to you and help you feel ready and you should start to feel more confident in knowing how to look after yourself.



Depending on your condition, transition can look a bit different. It is important to have conversations with your team to help you understand what will happen, what it looks like and what type of service you will transfer to.

Questions that you might want to ask could include:

- What should I know about my condition and medications I take?
- What does transition look like for me?
- What can I do to prepare for moving to adult services?
- Do I have a choice in which adult services I use? Can I go and see them before I transfer?
- Are there other young people I can talk to about moving to adult services?

Once you are in adult services your doctor will expect you to have more understanding of your condition. The role you play in making decisions about your own health changes is not your parents or carer's responsibility anymore. They can support you but not make those decisions. You will be responsible for attending appointments and taking any medication so it is good to try and start learning about your condition and take some responsibility when you are starting transition. Depending on your condition you may transfer to the same type of hospital service but in an adult setting, this might be in a more local hospital

to where you live. Sometimes there can be slightly different services in the adult hospital where you may need to go but it is important to remember that they are used to young people transitioning. Moving to the adult services you might find there are a lot more people with similar conditions and so it might feel busy, but young people have told us that waiting rooms are often a lot quieter! For some young people they don't need to continue attending hospital appointments when they transfer, but may be looked after by their GP. Wherever you are transferred to it is important to go to appointments even if you feel well.

If you have to go to hospital as an inpatient for any reason the adult ward might feel a bit different and there might not be so many other young people there. Although it may feel different to start with it will soon become familiar. It is important that you talk to the nurses on the ward if you are unsure of anything. As you are more independent you will not be expected to have a parent staying with you overnight, it's important to talk to the ward staff about if it is possible for them to stay if this would make you more comfortable. You can still have friends to visit too.

Transition can sometimes be a difficult time for parents and carers. They may have had to look after you and make decisions about your health for you. Sometimes it can take a bit of time for them to adjust to you becoming more independent. If you are finding it difficult it can be good to try and talk to them about it, it may feel like they don't trust you but might be more about them trying to do what they feel is best for you.



Top tips and strategies

One of the ways to prepare for transition is to learn about your condition. You might find the following ideas helpful:

1 Talk to your nurses and doctors. Ask them to explain anything you don't understand. Some things are complicated so don't worry if you have to ask them more than once!


2 As you get older and closer to transition you you could choose to attend part or all of your appointments at the children's hospital without parent/carer in the room.

3 Talk to your parent/carer about getting involved in some of the things that they look after such as booking appointments and getting prescriptions.

4 Find out about adult services, what might be the same or different. You could talk to your nurse or doctor to find out if you can visit before you transfer.

5 Know what to do and who to contact in an emergency.

6 Learn from your care team about the impact that your condition could have in your future, ask questions! Talk to them about what healthy living looks like – this might include exercise, eating or things like alcohol and sex. You can find out more about these on our transition website www.uhbristol.nhs.uk/transition/



Why is feeling anxious or worried important to talk about?

Anxiety is a normal human emotion, however if it gets in the way of us living our lives the way we want to or if you feel that you cannot stop or control feeling anxious or worried, then it may be helpful to try some of the suggested tips in this guide and from additional support services listed below. When we are faced with a threat or stressor (this can be actual or perceived) our body automatically responds by going in to 'fight or flight' mode, which is shown in a number of ways - a variety of which are listed below, perhaps you can think of some more examples:

When someone's anxiety is problematic for them, for instance it may stop them from doing certain things, this can often create a vicious cycle. The *vicious cycle* of anxiety is

when each of the symptoms listed above feed into one another, i.e. the more anxious thoughts we have, the greater our emotional and physical response, and so on.

When faced with uncertainty, e.g. awaiting the outcome of test results, our minds are prone to 'assuming the worst'. These negative thoughts happen automatically; often we believe our thoughts to be true without considering if there is an alternative, more balanced perspective. By challenging our negative automatic thoughts, we can reduce our anxiety and worry and feel more able to connect with what's important to us.



1

THOUGHTS

- Lots of racing thoughts, mind may jump from topic to topic
- 'What if?' worries, 'predicting' the future - often negative predictions
- Difficulty concentrating or remembering things

3

PHYSICAL SENSATIONS

- Muscle tension
- Sweating
- Heart beats faster
- Breathing more quickly

2

FEELINGS

- Tense or 'on edge'
- Irritable

4

BEHAVIOURS

- Sleep difficulties
- Avoidance of certain places/activities
- Finding it hard to sit still, restless

WHAT SUPPORT IS AVAILABLE?

It is important to make sure that you know the contact details of the teams that look after you in hospital. Your healthcare team are there to help support you with both your physical health and other things that are going on for you. They may be able to help provide support and ideas or know of additional services in the hospital that can help you. When you are looking to transfer it can be good to have the contacts for both your children's and adult teams. You can also contact the Young Persons Involvement Worker on 0117 342 7443.

Links to appropriate resources

1. You can find information on www.uhbristol.nhs.uk/transition/ about transition and different health conditions.
2. For information about health and wellbeing as a young person, you might also find information on the 'NHS Go' app that you can download onto your phone.



These toolkits have been written by NHS clinical psychologists and neuropsychologists working for University Hospitals Bristol. They have been co-designed with service users and healthcare staff. These toolkits are only intended to provide general advice and information. Please discuss your individual needs with your doctor or specialist nurse. If you would like more information about psychology services please go to:

<http://www.uhbristol.nhs.uk/patients-and-visitors/support-for-patients/psychological-health-services/>

We would like to thank patients and other healthcare staff for their contributions to this toolkit.

For access to other patient toolkits please go to the following address:

<http://www.uhbristol.nhs.uk/patients-and-visitors/support-for-patients/psychological-health-services/resources/>

For this leaflet in large print, audio or PDF format, please email patientleaflets@uhbristol.nhs.uk

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