Part 1. Supporting transition from child to adult services

A guide for healthcare professionals

About 20% of the population in the UK are under 18 and about 700 children at any time are in the process of transition from children to adult services within the NHS.

Guidance from NHS England and the NHS Long Term Plan recommends health professionals collaborate with their patients to ensure services are fit for now and the future.

Whilst it can be difficult to predict if young people with bladder and bowel conditions will need long term care and support, starting conversations early ensures improved care experiences for the young person and their family.It may also have a positive impact on long term health outcomes, attainment of life goals and ensures the best use of NHS resources. It is not acceptable to assume that a young person will not require transition and therefore ignore this element of care.

Developmentally appropriate health care is essential. Health care professionals who work with young people, should engage with them, and support them to learn how to manage their own health care as part of the process of individualised transition – a process that happens over years, not overnight. The recommended age to begin the process is eleven, or if the young person is older than this, as soon as they engage with a service. Transition is not considered complete until the adult team have taken over the healthcare. This is usually from about sixteen to eighteen years old, but in some cases may be up until age twenty-five.

Currently there is a variation in transition processes across the NHS, with some areas more active in transition than others. This can leave professionals feeling unsure as to where to begin.

This Bladder & Bowel UK guide (Part 1) will help you and your team understand the process of supporting young people transitioning from child to adult services and ensure the pathway you develop locally includes the three phases needed for successful transition and standardised practice:

Supporting transition from child to adult services

- Timely preparation started within child and adolescent services.
- Actively managed and co-ordinated transitions between child and adolescent and adult services.
- Continuous developmentally appropriate support from adult services.

Starting the conversations early with young people in your service and their parent/carers, around what transition means for them is important and for the questions and discussions that are needed to take place and for both you and them to feel prepared.

Each young person's transition should be individualised. As a health care team, you will be able to provide your patients with specific information on the pathway used locally for their condition and how this will be adapted for their needs, if required.

The Bladder & Bowel UK team are also here to support you and you can contact our helpline for further advice and support. The team of specialist nurses have experience in transition and would be happy to help you.

We also offer Bladder & Bowel UK Lunchtime Learning sessions to guide services new to developing the transition process and building a transition pathway.

What is the difference between transfer and transition?

Transfer is a single event of moving the young person's care to adult services. It is not empowering and occurs without their involvement. This has been proven to impact negatively on the young person's experience, as well as their immediate and long-term health and well-being.

Transition describes the recommended process of preparing and planning the move from children's services to adult care for individuals with long-term health conditions. It is purposeful and encompasses the young person's individual, medical, psychosocial, educational, and vocational needs through access to professionals experienced in these areas. Furthermore, it never assumes or expects of the young person.

Supporting transition from child to adult services

This is not a rushed process, in fact the young person and everyone involved in their care works together as a team over time. This means there will be lots of discussions about what would be best for them, and all plans are made together, with their wishes and feelings a priority and in line with their development. It can take time for both health care teams and the patient to feel prepared for the move. **Starting to think about adult services and the process of transition**

Young people and their families will have become comfortable with the children's team that have looked after them so far. However, early collaborative working allows them time to meet and get to know the new team, which can reassure them and support their move.

At what age should transition begin and why is this important?

It is recommended that the process commences at or soon after the age of eleven with a long-term health condition, or as soon as possible for any older than this who are new to a children's service.

Initiating transition at an early age has been shown to improve the long-term outcomes for patients, achievement of their life aspirations and attainment of their goals. This is because the process enables them the time needed to gain the knowledge and skills about their condition, ask questions and take a pro-active approach to their health needs, enabling ownership of their health care plan. It ensures they have all the information and time they need to be fully informed about their care and what to expect in adult services.

This is important because children's services are often unable to provide some of the care and advice a child/young person needs as they get older, meaning that the important conversations about impact and interactions of their health needs on travel; education; career or sexual relationships can take place in a grown-up setting rather than a children's ward or department.

Supporting transition from child to adult services

What does good transition look like?

1. Patient centred approach - appropriate for their age; language and development.
2. Advocates privacy and dignity.
3. Ensures comprehensive assessment.
4. Clinicians work on building trust and rapport with the young person.
5. Appropriate tailored information and advice is given.
6. Inclusion in decision making and facilitating choice.
7. Opportunity for open discussion and questions and to find solutions together.
8. Allows time to link with peers with similar problems.
9. Associates with support groups and professionals that can help the young person and they can access in order make sense of any feelings or concerns around their condition.
10. Maintains hope for improvement or resolution of their condition as appropriate.
11. Involves parents and carers.
12. Never assumes.

Benefits of good transition

- Improved follow up
- Reduces missed out-patient appointments and dropouts from care.
- Patient and parent satisfaction.
- Improved condition control and knowledge.
- Improved documentation of adolescent issues.
- Improved health related quality of life morbidity and mortality outcomes.
- Reduces possible concealment of issues.

Supporting transition from child to adult services

Do we need a transition pathway?

A pathway is helpful in navigating the process of transition.

An effective transition pathway design recognises that the process coexists alongside rapid physical and psychological and social changes for the young person. It is solution focused, promoting collaboration and empowerment to avoid assumptions and remain patient and family centred.

A pathway helps to break the phases of transition into stages based on the young person's development, environment, psychosocial and socio-economic needs. This facilitates the young person to gain the knowledge and skills to manage their condition.

An effective pathway is inclusive of a multidisciplinary team of professionals who can help collaborate with the young person and so inform individual care, advice, and support. An example of a published pathway available for use is: Ready, Steady, Go. More information can be found here.

Does a transition pathway need to be subspecialty specific?

No. A generic pathway such as Ready Steady Go can be adopted by and adapted to your local service, because many of the issues a young person experiences during transition are generic regardless of their long-term condition.

Do we need a transition clinic?

No. Supporting young people with the knowledge and skills needed to manage their health care can occur in any clinic.

Supporting transition from child to adult services

Can transition begin without an identified adult team to which the young person's care can be transferred?

It is best practice to ensure joint clinics with the adult team and have already identified the adult team prior to initiating transition discussion. However, transition should not be delayed in the absence of this. Paediatric teams can instead focus on adequate preparation whilst an adult service is identified. This is also the case for those young people transitioning to primary care for their long term follow up.

Can a young person with learning disabilities undergo transition?

It is a misconception that young people with significant learning disabilities cannot be involved in their transition. It is recommended that emphasis is on inclusion whilst supporting their parents/carers through the process.

Working jointly with parents and carers alongside colleagues in other specialised professions, such as learning disability teams, transition social workers and education staff can assist a holistic transition for the young person and encourage health care professionals to develop their knowledge and skills.

It is important for those working in health care that they identify any gaps in their knowledge about the young person's needs, including accessing relevant training e.g., about learning disability and autism.

Training available includes:

- The Oliver McGowan Mandatory Training on Learning Disability and Autism available at: www.hee.nhs.uk/our-work/learning-disability/current-projects/oliver-mcgowan-mandatory-training-learning-disability-autism

- www.skillsforhealth.org.uk/services/item/22-elearning-healthcare

Supporting transition from child to adult services

Adult services need to make reasonable adjustments for young people with disabilities and additional needs. This may include allowing parents or carers to attend clinic appointments and supporting with any care. It is important that all health care professionals recognise that many of the adjustments that need to be made for the young person will improve their experience of care.

What about if the young person and/or their family already has other significant challenges in their life – do we still discuss transition?

The decision is made together between the young person their family and the lead clinician in their care about when the time is right for them. You may feel they are ready sooner than they feel they are or can be. Differences of opinions with young people and/or their families and the clinical team need to be managed using the tools within the transition pathway, that your team adopts.

Having a long-term medical condition is challenging for a young person and their family. Becoming an adult presents further challenges for them. By ensuring the young person has a trusted team, that gets to know them and their unique situation and who facilitates working through their health issues can alleviate concerns about moving to adult services and promote good outcomes.

How can you help the young person get ready?

You can provide support and advice by:

- Teaching the young person about their illness or condition and treatment, other options, and possible side-effects of these. By enhancing their understanding and having appropriate support from you they are empowered to make informed decisions about their care.

- Providing clinic appointments when they attend without their family for some or all the appointment – this would only happen when they have identified they are ready, which may need some specific support and encouragement from you.

Supporting transition from child to adult services

- Providing information on who to contact in an emergency, or if they have questions or concerns, so they know where to get help if needed.

- Having discussions that make it easier for them to understand how their condition or illness links with any education and career plans.

- Signposting them to support networks that are available locally and nationally. These include but are not limited to:

- Mencap
- Council for Disabled children
- WellChild.org
- Contact
- Kidz to Adultz Magazine

- Supporting them to understand the benefits of maintaining a healthy lifestyle, and providing health promotion around lifestyle choices as appropriate, which may include but not be limited to exercise, diet, smoking, alcohol consumption, recreational drugs, sex, and relationships.

The importance of parents and carers?

The transition process is focused on the young person, but it is important to remember that their family may still be involved in their care and be able to offer useful advice and support as they have the experience and understanding of their child's illness or condition.

It is useful to have discussions with parents/carers, as appropriate, about any questions they may have so that they can continue to support the young person in an informed way.

t is normal for parent/carers to feel worried, but discussing their feelings can be helpful to you all as you work through the transition process and it is quite acceptable for care needs to be negotiated during this period. It is also important to allow for a period of flexibility with this process and enable the young person to voice what they would like from their parents and carers as they transition.

Supporting transition from child to adult services

Parents and carers can also be very supportive with the practical aspects of their young person's care, such as arranging prescriptions or appointments or supporting them to ensure all the young person's questions are answered in clinics, whilst the young person is learning to be independent with this.

The development of Transition within the NHS is evolving, and we intend to keep this guide updated in line with best practice guidance.

Relevant reading

- Department of Health – Transition: Moving on well 2008
- Essence of care 2010
- CQC - From the Pond to the Sea 2014
- The Care Act 2014
- NICE guidance (NG43) and Standard 2016 (QS140)
- RSG (2016) Implementing Transition – improves long term outcomes.
- It happens to me to 2018
- Community Currencies for transition NHS England 2020/2021
- Core capability Framework for the Care of Young People and Transition (2022)
- National training package for the care of young people and transition Burdett Trust 2022
- National framework for transition 2023
- A guide to using benchmarking for Transition 2023
- Transition information Network @Council for disabled children.org
- Alder Hey 10 steps transition Pathway @tensteps transition.org
- Ready Steady Go Pathway@readysteadtgo.net

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.