



# Alström Syndrome UK

Strength for today, hope for the future

## Transition in Healthcare Growing up with a Long-term Health Condition

### **What does Transition mean?**

Transition is a term used in healthcare to describe changes that happen at different times in a young person's life (like moving from primary to secondary school). It also includes developing the young persons' knowledge and skills to live their life in the best way possible while coping with a long-term health condition/s.

The transition journey or process starts early, usually around year six of primary school. It not only covers medical condition/s, but it includes areas such as vocational choices, leisure activities and emotional well-being.

When young people take part in the Alström clinic at Birmingham Women's and Children's Hospital (BWCH), the Transition Care Co-ordinator (TCC) will start chatting to them about transition when they get to about year 6 in primary school. The TCC and some of the Healthcare Team will talk about different aspects of their life such as how they manage their health condition/s, what they are doing at school or college, or how they manage relationships.

### **When should Transition start?**

Transition ideally starts around the age of 11, as this is a natural time for change in a young person's life. Young people all eventually leave school in the same way and they will eventually leave the Alström clinic at BWCH. Most young people will eventually move up to adult services, the Alström Team will give them and their families lots of help and support to deal with the move.

### **Why is Transition so important?**

Research has shown that when young people and their parents/carers have had time to talk about managing changes and learn skills, they find it easier to cope with the transfer to adult care. The sort of skills they learn are things like preparing and asking health professionals their own questions or seeing one of the health team on their own.

## **What happens in Transition?**

When young people take part in the Alström clinic they see the TCC who will work with the young people to become more independent and build confidence to develop their transition skills. The TCC sets up a Personalised Care Plan called My Life, My Future (MLMF) which covers different aspects of the young person's lives, the skills and knowledge they are developing, along with the young person's thoughts, ideas and comments. The TCC works to:

- ✚ Improve the young person's communication and decision-making skills.
- ✚ Encourage them to take control of their self-care.
- ✚ Give them opportunities to speak up for themselves (self-advocacy) and to be seen independently (without parents/carers).
- ✚ Work with the young people to think about their future (this includes school/college/apprenticeships, etc).
- ✚ Support them to get the best from life regardless of their condition or disability.
- ✚ Work with parents/carers to give them guidance and support to understand their young person's needs.
- ✚ Working with parents/carers to give them guidance and support.
- ✚ Preparing, planning, and coping with transfer to adult services.
- ✚ Gives advice and confidence to the young people to build up their self-advocacy skills so that they can speak to other healthcare staff independently.

## **Top Tips for young people when speaking to their Healthcare Team**

- ✚ Have your own list of questions ready.
- ✚ Learn more about your medical condition/s, so that you are prepared to talk about it as you build your skills and confidence.
- ✚ Be confident and answer questions honestly.
- ✚ Ask the Alström Healthcare Team to use simpler language if you do not understand what they have said.

## **When will transfer happen?**

The current Birmingham Women's and Children's Foundation Trust policy is that young people should transfer to adult care from the age of 16. In the Alström Team the timing of transfer will depend on several factors, for example:

- ✚ Maturity
- ✚ A young person's ability to manage their condition
- ✚ Preparation for transfer

The BWCH Alström Healthcare Team know that transferring to adult services can make some young people/families feel a little nervous or worried. When you transfer to the Adult Alström Service which is held at the Queen Elizabeth Hospital (QEH),

Birmingham, some of the BWCH Healthcare Team will join you at your first adult appointment to help you settle into your new clinic.

Use the T-KASH (Transition Knowledge and Skills in Healthcare) Circle to think about different aspects of a young person's life and how they can build up their knowledge and skills to live the best life possible.

