

Transition to the Adult Gastroenterology Team

This information sheet aims to explain about the transition process of your care to the Adult Gastroenterology Team and what it will mean for you. Remember that if you have any questions about your transition, please talk to a member of your Children's Gastroenterology Team.

What is transition?

It is the purposeful and planned movement of adolescents with a chronic medical condition from paediatric to adult-oriented healthcare systems/care providers.

“Transfer” is the point of handover of care to the adult healthcare team, and should be considered part of (and not necessarily the end of) transition.

There are inherent differences between paediatric and adult care: paediatric care is more family focused, with parents and caregivers playing a crucial role in consent and guidance; adult care advocates for the patient independence and while family members can still support, they are no longer directly involved in the decision making. Moving from one model to the other requires a structured transition process over some time and cannot just happen on one occasion or without adequate preparation.

Why it's important for you to move to adult care?

As you are growing up both physically and emotionally and developing into a young person you may feel that you have grown out of Children's Services and feel ready to move on to a more adult setting and to start learning how to take responsibility for parts of your life, including your health. We will help you to gain independence and support you with any issues that may be worrying you.

What are the differences?

Your care in the Adult Services will be by a nominated Consultant and their team. You may not always be seen by your Consultant but by a member of the team which consists of; a Specialist Registrar, an Adult Inflammatory Bowel Disease Nurse (IBD Nurse) and a Dietician.

The Team works very closely with your Consultant and will discuss any issues that are concerning you, ensuring that you are always given continuity of care and support.

More time will be spent talking to you during your appointments rather than your parents/carers. You may feel nervous when you first attend the adult clinic and want your parents or carers present until you feel ready to start seeing your Consultant or Team on your own, however you can still ask your parents/carers for advice on what questions to ask. The appointment times will generally be shorter.

Your first appointment will always be a face-to-face appointment. Subsequent appointments maybe either via telephone or video call.

When will this happen?

Everyone is an individual but most young people move to the care of an Adult Gastroenterologist Consultant between 16 and 18 years old. When you reach the age of 14 years a member of the Children's Gastroenterology Team will start the gradual process of preparing you for your transition, using the Ready, Steady, Go paperwork.

This process is to help ensure the areas around your ongoing care needs are met and that you are confident once the time is right for you to move onto the adult service. It's important for you to discuss with your parents/carers, and the Children's Gastroenterology Team about your transition as they can help to prepare you for this process also.

Adolescent Transition Clinic

When you reach the age of 15 years and you feel the timing is correct for you, you will be given the opportunity to attend an appointment in the adolescent transitional clinic. These clinics are held on the second Tuesday of every month between 16.00 – 18.00 hours in the Jenny Lind Department, where you currently come for your appointments.

Some of the members of the Children's Gastroenterology Team will be present at this appointment but you will also have the opportunity to meet with one of the Adult Consultant and Adult IBD Nurses who will be responsible for your care in the Adult Gastroenterology Service.

Following this appointment if you then feel the timing is right for your care to be transferred to the adult service a member of the Children's Gastroenterology Team can join you at your first clinic appointment with the Adult Team.

Do I have a choice where to move to?

Yes, you will be offered a choice of where you would like your care to continue. The Adult Gastroenterology clinics are either held in the medical outpatient's area on level 3 either in the East Atrium at the Norfolk and Norwich hospital or at Cromer hospital.

While paediatric gastroenterology care is only offered at tertiary level regional centres, adult gastroenterology and adult IBD services are more widely available across the region. Depending on the area you reside in, you may wish for your care to be transferred under the local Hospital closer to home that offers an adult gastroenterology and IBD service. Examples include King's Lynn, Ipswich, James Paget and West Suffolk Hospitals.

What to do to help prepare you

- Learn about your condition and treatment.
- Start to take responsibility for your medication and appointments.
- Practise asking questions in the children's clinic
- If you feel ready to make the change inform a member of Children's Gastroenterology Team.
- Try spending time without your parent or carer in clinic.
- Keep important phone numbers and dates in your diary, mobile or calendar.

- Find out who to contact if you require help urgently or in an emergency.
- The use of digital health technology (i.e. phone apps etc.) is encouraged as they offer valuable educational material, including transition modules (e.g. “myIBD”, “Doc4me”, “MyIBDcare” apps). You can talk to our team’s members if you feel you need further guidance and support about these resources.

If you need help between clinic appointments

If you require any additional advice, support or have concerns about your condition you can contact either the: -

Help Line for the Adult IBD Nurses: - 01603 288403, calls to the helpline will be dealt with Monday – Thursday 08.30 – 14.00hrs (not including bank holiday). It may take up to 48 hours to return your call so if the call is urgent you are advised to contact your GP.

Outside these times contact your out of hours GP service or Local Accident and Emergency Department.

What happens if I need to come into hospital?

If at anytime you should need to be admitted into hospital because you are unwell due to your inflammatory bowel disease you are most likely to be admitted to Guist Ward at the Norfolk and Norwich Hospital on level two centre block. When you are admitted to the ward please ask the nurses to contact the IBD Specialist Nurse. Initially following your transfer of care to the Adult Service there may need to be an ‘overlap’ of your care between the Children’s and Adult Gastroenterology Teams.