



British Society of Paediatric Gastroenterology Hepatology and Nutrition

A statement on transition of young people with IBD to adult healthcare services

Transitional care is ‘the purposeful, planned movement of adolescents and young adults with chronic physical and medical conditions from child centred to adult oriented healthcare systems’. The transition period is well recognised as a vulnerable period during which unaddressed healthcare needs may have long-term consequences. Structured transition care can improve control of chronic digestive diseases and long-term health-related outcomes.

The transition process for Inflammatory Bowel Disease (IBD) is one of empowerment, that equips young people with IBD with the knowledge and skills necessary to manage their own condition in paediatric and adult services whilst ensuring the adult IBD team are engaged and ready to receive them (adapted from Cochrane Review).

Paediatric Gastroenterology teams across the UK will as a matter of routine be involved in the care of the adolescent with IBD and therefore it is fundamental to have in place an overlap with both paediatric and adult gastroenterology care that is a core element of every structured transition service. IBD teams therefore need adequate resourcing in order to:

- ***Enable parents and carers to feel confident that the adolescent with IBD will seek help when appropriate and that adult services will be able to care appropriately for them once transition***
 - ***Empower the young person with an understanding of the disease, current treatment options, future health issues and an understanding of levels of care that exists in primary and secondary care services and how to access these.***
 - ***Ensure health professionals on the paediatric and adult teams develop skills that are necessary to help nurture autonomy for the young person with IBD. Suboptimal training in adolescent care is a barrier to successful transition.***
 - ***Develop a model for transition appropriate to the network, for example – specialized adolescent clinics, or mechanism for careful handover to a named adult gastroenterologist and named specialist nurse where face to face joint clinics are not possible.***
1. Each paediatric unit that looks after young people with IBD should have a written policy on transition that is agreed by all members of the multidisciplinary team and targets adult services within the network.
 - a. Follow relevant national guidelines
 - b. Use material available from charity groups and other organizations e.g. ‘transition moving to adult care’, ‘cool zone’ (www.circa.org; www.crohnsandcolitis.org.uk)
 - c. Make it specific to your network, based on local expertise, staffing, resources and geography. Define and agree specific aspects of service delivery (e.g. separate young adult clinics, endoscopy under sedation, out-of-hours telephone support or enhanced follow-up)
 - d. Agree between paediatric and adult team exactly what information should be included in summary sent to the adult gastroenterologist at point of transition, including whether disease reassessment prior to transfer of care is needed. Consider a network specific proforma to ensure all relevant information is passed on.
 - e. The receiving adult teams will also need to agree their part of the transition pathway (e.g. RSG programme). The paediatric team should understand and share this information with young adults as part of the transition planning. There needs to be clarity around the receiving team (with an emphasis on a follow on program, e.g ‘Hello to Adult services’) to answer questions such as-

- i. Who will look after me? How do I get urgent help?
 - ii. What happens when I move for further education or work?
- 2. There should be a named transition coordinator to oversee the process (key worker).
- 3. A personalized healthcare transition plan should be formulated with the young person with IBD and their family/carers and regularly reviewed and updated. This should:
 - a. Include IBD specific education (*disease location, previous history, medication, prescription charges, any job restrictions, rights at work or if off work unwell, precautions on immunosuppression, travel vaccinations*), differences in adult service (*IBD help line, endoscopy*)
 - b. Take into account the medical, psychosocial and vocational needs of the young person, including life-style, future health concerns, educational/employment goals, psychosocial health, sexuality and reproduction²
 - c. Provide for any special circumstances or additional needs.
 - d. Identify any co-morbidities or specific needs that may need primary care or other specialties (e.g. liver disease, stoma care, emotional or special educational needs, etc)
 - e. Use a validated tool if possible (e.g. Ready steady go, TRAQ) or adapt trust or regional paperwork
- 4. Timing of transition - Start early and personalise the transition for each patient
 - a. Process needs to start for both the young person and carers well before the actual date of transfer of care with opportunity for the adolescent to have confidential discussions with the specialist nurse (or named transition keyworker)
 - b. Ongoing assessment of readiness for transfer is vital. This should include an understanding and assessment of mental capacity, and identification of those with additional need for emotional or psychological support to allow smooth transition.
 - c. Transfer of care to adult services needs to be timed to allow for major educational and physical milestones, but will generally be around age 16-17, ideally at a time when disease is stable and controlled, and in most cases completed before the 18th birthday.
- 5. Audit and review of service –
 - a. While there are no measurable health outcomes for IBD, the process of transition of young people with IBD should be evaluated regularly.
 - b. Individual IBD teams that look after adolescents and young adults with IBD should have audit mechanisms in place to ensure compliance with their chosen interventions and transition policy, and
 - c. They should aim to assess key performance indicators and work with their respective adult counterparts to evaluate disease-based long term outcomes.

References:

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3. Tuchman LK, Slap GB, Britto MT. Transition to adult care: experiences and expectations of adolescents with a chronic illness. *Child Care Health Dev* 2008;34:557-63.
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5. Department of Health. Transition: Getting it right for young people. Improving the transition of young people with long term conditions from children's to adult health services, National Service Framework for Children, Young People and Maternity Services, 2006

6. 'From the pond into the sea'; Children's transition to adult health services: Care Quality Commission, 2014
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8. Implementing transition: Ready Steady Go, Nagra et al, *Arch Dis Child Educ Pract Ed.* 2015 Dec; 100(6): 313–320.
9. NACC,CICRA.TransitiontoAdultHealthcare:GuidanceforHealthProfessionals,2008
www.ibdtransition.org.uk/downloads/IBD_Transition_Guide_Health_Professionals.pdf
10. RCPCH Quality Standards for PGHAN (January 2017), Standard 3

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