

BOWEL ADVISORY GROUP

Adolescent transition in small bowel transplantation

Background

The medium to long term survival following intestinal transplantation has improved in the recent years thus posing new challenges to the intestinal transplantation teams managing this complex patients. As documented in other solid organ transplantation groups, one of the vulnerable period in the paediatric population is the smooth transition to adult transplant programmes.

Currently there is lack of specific provision of transfer or any arrangements in place for 'safe transition' of paediatric intestinal transplant population to adults.

The National Service Framework (NSF) for Children and Young People (DH, 2003) recognizes that transition should be a guided, educational, therapeutic process, rather than an administrative event. Effective transition must also allow for the fact that adolescents are undergoing changes far broader than just their clinical needs. Transition arrangements are anticipated to cover transition in the broadest sense to include social care, education and employment rather than just within hospital services.

Challenges in the Intestinal transplantation field

1. Geographical
2. Children with learning and physical disabilities
3. Children with opiate dependency
4. Children with ongoing medical and surgical problems

Process

Age of transition:

There is no correct age for transition and different recommendations for different ages exist. Ideally the concept of transition should be introduced at the age of 12 with the first appointment for transition with the multidisciplinary team to be held at the age of 13-14 years.

Adolescent transition team

1. A key worker needs to be identified in the multidisciplinary adult and paediatric team who need to keep in regular contact throughout the transition process.
2. A named physician needs to be identified in the adult team
3. Additional support staff need to be appointed within the adult programme and/or paediatric programme to allow for the smooth transition e.g.
 - Adolescent transition nurse
 - Adolescent youth support worker
 - Clinical Psychologist

Key objectives

The key objectives need to be identified at the adolescent clinic for the following:

- Set objectives for the year
- Identify targets
- Work with key workers to meet goals

Appointments

The frequency of appointments with each individual adolescent is varied depending on the understanding of the overall process and the support offered by the family at home.

At the end of year 13 and 14

Meeting with parents and adolescent transition team at children's hospital to record the objectives achieved and action plan for any missed objectives.

The respective children's hospital team makes the adult team aware about the number of adolescent that need to be transitioned.

- A summary is produced about the past medical problems
- Current medical /surgical /psychological issues are clearly highlighted
- A photocopy of the operative notes is provided to the adult team

At year 15-16 (depending on each individual child)

First contact with adult team of adolescents in transition process

After initial discussion with Cambridge agreed plan

- Once a year adolescent clinic at Cambridge
- Once a year adolescent clinic at Birmingham Children's Hospital

Key members from both teams

Children's hospital team	Adult team
Physician	Physician
Specialist Nurse	Specialist nurse with an interest in transition
Adolescent transition nurse	? in future- adolescent transition nurse
Dietitian	Dietitian
	Clinical Psychology support

During the clinic

- Key objectives to be identified
- Progress over the last 2 years reviewed with the adult team
- Missed objectives identified and action plan reviewed with the adult team along with the parent and young person

At year 17-18

- Same structure for clinic arrangements as above
- Review the key objectives
- De-brief about the missed objectives

At year 18-19

Care handed over to the adults after mutual agreement within the paediatric team and adult team

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