

Statement of Need

Development of the Adolescent Transition Service in UK for Bowel Transplant patients

What is Transition?

Transition is a multifaceted process, which includes the event of transfer and attends to the medical, psychosocial and educational/vocational needs of young people with long term conditions and/or disability and the needs of their parents/caregivers (Blum et al 1993). Transition by its definition is pivotal to the development of self-management practices for young people, thus allowing continuous improvement and quality of care throughout the transitional care programme.

Therefore, the aims of transition are to:

- Provide high quality, co-ordinated, uninterrupted health-care that is patient-centred, age and developmentally appropriate and culturally competent, flexible, responsive and comprehensive with respect to all persons involved.
- Promote skills in communication, decision-making, assertiveness and self-care, self-determination and self-advocacy.
- Enhance the young person's (YP) sense of control and interdependence.
- Provide support for the parent(s)/guardian(s) of the young person during this process to maximise lifelong functioning and potential (McDonagh 2008; Viner 2008).

Transition has been highlighted in many national policy and guidance documents in recent years as an integral component of care for all young people including those with long term conditions and/or disability. Transitional care is underpinned by the core principles of adolescent medicine and development of young person friendly health care services (Kennedy & Sawyer 2008; Department of Health 2011). The department of Health documents (DoH 2006 & 2008) highlight the need for the development of a seamless service for young people transitioning between paediatric and adult services. Ensuring a seamless transition is one of the challenges the transition team at BCH face, as the young people sometimes present with complex needs and are cared for by more than one speciality.

Successful transition

Several steps have been identified that are paramount to the successful transition of a child with special needs from a family-centered pediatric system to a patient-centered adult long-term care system, including the following:

1. Comprehensive care that is coordinated and managed through a medical home (usually a primary care provider but in some instances a tertiary care center or a subspecialty practice)

2. Access to healthcare financing
3. Education of adult providers in managing chronic conditions previously limited to the pediatric population

Ongoing, coordinated communication between patients, families, and pediatric and adult healthcare providers to facilitate transition and transfer

Background for intestinal transplantation

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.

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

Number of patients

The following describes the current numbers of patients that require the Transition team's input:

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- 3 patients aged between 18-24 years – ready for transition
- 8 patients aged between 14-18 years.
- 10 patients aged between 10-14 years
- Number of patients post transition at Addenbrooke's – 1

The number of patients within the categories above will never diminish and are expected to remain at a consistent level as patients pass through each category and therefore will require a consistent level of Transition support to prepare them for their transfer to adult services and ensure they are able to function responsibly within adult services and cope with the changes and challenges transition brings. In short, there will always be a number of patients at both BCH and QEHB that require the input of a Transition team.

Role of MDT team members

Clinical Nurse Specialist

The Clinical Nurse Specialist (CNS) is the lead nurse for Liver and small bowel transition and endeavours to first build a trusting relationship with the young people (YP) and this takes time. Building a relationship with the young people and their parents is integral to a successful and smooth transition to adult services, as each will present with their own individual set of needs.

The CNS key duties are described below:

- Advise on the implications of the investigations being undertaken
- Organisational aspects of patient care i.e. referrals, appointments and follow up care
- Ethical dilemmas – using expert knowledge to guide patients
- Act as the patient advocate to help facilitate their decision making regarding their future treatments.
- Assess treatment options
- Assess levels of psychological distress
 - Ø Noting previous psychiatric history
 - Ø Any major life crisis events
 - Ø Recent bereavements
- Social assessment, including family and sibling support
- Educational and work related needs
- Financial assessment
- Telephone call updates with patients / clinical team / outside agencies
- Symptom control
- Rehabilitation
- Spiritual support
- End of life care
- Bereavement support
- Administrative duties i.e. Typing correspondence to outside agencies (such as GP), Faxing, filing correspondence as required, chasing blood results, inputting data.

Youth Worker

The youth worker role is to establish a trusting and understanding relationship, so that the young people can feel comfortable in their feelings and beliefs thus assuring them that the role is to support them and not make Judgements on their lives to build up a level of trust where young people want to share other parts of their lives with the transition team (educationally, socially, emotionally, vocationally etc).

The roles of the Youth specialist worker are:

- Provide psychological and social support
- Supporting the development of common assessment framework (CAF)
- Support YP with learning difficulties / compliance issues
- Supporting YP through crisis management
- Assisting YP adjust to care in adult services
- Visit patients on wards and in OPD with Transition nurse or independently
- Provides some form of respite for long stay patients
- Helps facilitate evening youth club at BCH / QEHB for Liver patients
- Supports YP whilst they have procedures undertaken
- Liaison with other agencies e.g. GP, Social services to assist the YP
- Provides vocation/ educational support
- Advocating services within the hospital - to help young people with other services and to keep young people's needs in the forefront
- Assists YP with housing issues
- Assists YP with social benefits
- Assists YP that have a caring responsibility to family a member
- Liaises with Connexions to assist YP get career choices
- Supporting other family members if patients have behavioural problems
- Dealing with young people and their families concerns to provide them with an honest account of the adolescent process
- Bereavement support when required
- Support with sexual health, drug, alcohol and substance abuse issues
- Works with the Royal National Institute for the Blind (RNIB) when required

Talking with Schools/ Colleges/ Universities (if the Patient or family want this)

Clinical Psychologist

The role of the clinical psychologist is crucial in supporting adolescence through a difficult period of their lives. There are several transition that an adolescence is undergoing and it is vital to support the adolescence in these issues

The roles include:

1. Assessment of the adolescent and family
2. Understanding the family dynamics so that support can be given
3. Cognitive assessment so that support can be offered according to the level of commitment
4. Dealing with peer group pressure
5. Support through the life span and developmental tasks through the adolescence (Table 1)
6. Joint clinic consultations- liaison with other services

7. Intervention in difficult psychological situations
8. Attendance at clinics

There will be children with complex needs/learning difficulties etc and require a lot of input and in this situation the parent/carer also needs support and advice who will need support of the Multidisciplinary team for smooth transition.

- Below are some of the documents that are utilised to bring about best practice within the department, and which underpins the transition pathway from paediatrics to adult services.
- National Service Framework for children, young people and maternity services (2003,2004)
- Every Child Matters (2004)
- Transition: Getting it right (2006)
- A Transition guide for all services. Key information for professionals about the transition process for disabled young people. (2007)
- Growing up Matters: Better transition planning for young people with complex needs (CSCI, 2007)
- You're Welcome - quality criteria for young person friendly health services (2011)
- CMO Annual Report 2007
- Transition. Moving on well 2008
- Healthy Lives, Brighter Futures (2009)
- Getting it right for children and young people: overcoming cultural barriers in the NHS so as to meet their needs. (2010)

Administrative support

There is also a need for administrative support. A proportion of what the transition team undertake could be carried out by an administrative person as letters and other admin duties are often completed late or not at all due to other patient centred demands.

Support for the Proposal

The transition programme is underpinned by you're Welcome doc (2011) and Every Child Matters (2004).

This proposal is submitted and fully supported and endorsed by both adult and paediatric teams at all the four small bowel transplant centres. All teams recognise the need to expand the Transition team to allow the transition process to be fully functional and support patients as they progress through adolescence and transition from a Paediatric Hospital setting to an adult environment. The team's proposal also grows out of a shared interest in providing services for YP and their families/carers. This will ensure that we meet the needs of the YP and continue to improve the process and structure of transitional care (McDonagh et al 2006, Webb et al 2010).

Table 1.

Life Span Developmental Tasks and Issues for the Adolescent and Adult by Age Group

Domains	Mid Adolescence (14–16 y)	Late Adolescence (16–19 y)	Young Adulthood (19–35 y)
Physical	Coping with body image and limitations in physical functioning	Coping with body image and limitations in physical functioning	Gradual or acute decreases in physical functioning; burden/complications with onset of common illnesses of adulthood
Social and family relations	Peer acceptance of physical appearance/limitations; coping with stigmatization; lack of social support for SBTx issues	Decisions about dating; increasing independence from family; lack of social support for SBTx issues	Decisions regarding life partner and reproduction; coping with loss of normative family life cycle; finding a social group/network
Emotional	Managing anxiety-provoking medical procedures; maintaining emotional adjustment during period of critical transitions	Managing anxiety-provoking medical procedures; maintaining emotional adjustment during period of critical transitions	Managing anxiety-provoking medical procedures; avoiding arrhythmia-related anxiety/phobic reactions; avoiding despair, depression, or anxiety; maintaining emotional/mental health
Education and vocation	Coping with possible intellectual and/or learning disabilities	Selecting educational and vocational goals appropriate to present/future abilities	Stigmatization/discrimination in obtaining employment; maintaining employment during medical crises
Medical	Taking some responsibility for medical care; learning appropriate health behaviors	Increasing responsibility for medical care; transition to adult care; knowledge of diagnosis, prognosis, and associated health behaviors	Primary responsibility for medical care; knowledge of prognosis; reoperation(s); SBTx complications; coping with medical procedures and hospitalization; coping with procedure-related pain
Health behaviors	Avoiding initiation of risky health behaviors; maintaining appropriate weight and getting exercise; maintaining oral hygiene and preventing endocarditis	Regular medical follow-up; avoiding risky health behaviors; maintaining appropriate weight; getting	Regular medical follow-up; avoiding risky health behaviors; maintaining appropriate weight; getting appropriate exercise; maintaining oral hygiene and preventing endocarditis

		appropriate exercise; maintaining oral hygiene and preventing endocarditis	
Personality and identity	Integration of SBTX into self; acceptance of being different and unique	Lack of control over health outcomes; increasing independence	Balancing independence and interdependence with family and friends

Table 2 : Multidisciplinary Liver and Small bowel transplant transition teamPaediatric centre

CORE TEAM	DESIRABLE
Consultant Physician/Surgeon (0.4 WTE)	Pharmacist
Coordinator/Nurse specialist (Band 7 0.4 WTE)	Play specialist
Clinical psychologist (Band 8a 0.4 WTE)	
Specialist family support worker (Band 4 0.3 WTE)	
Youth worker (Band 4 0.3 WTE)	

Adult centre

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Consultant Physician/Surgeon (0.4WTE)	Pharmacist
Coordinator/Nurse (Band 7 0.4 WTE)	
Clinical psychologist (Band 8a 0.4 WTE)	
?Specialist family support worker (Band 4 0.3 WTE)	
Youth worker (band 4, 0.3 WTE)	

? administrative support

TRANSITION PATHWAY

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.

Key objectives

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

- Set objectives for the year
- 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.

13 and 14 years of age

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

15-16 years of age (depending on each individual child)

First contact with adult team of adolescents in transition process

After initial discussion with Adult transplant team agreed plan

- Once a year adolescent clinic at Adult centre
- Once a year adolescent clinic at paediatric centre

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

17-18 years of age

Same structure for clinic arrangements as above

Review the key objectives

De-brief about the missed objectives

18-19 years of age

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

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