Transition from Paediatric to Adult care in Congenital Hyperinsulinism

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Why transition?

- Children with HH need regular multidisciplinary team input – dietetics, psychology, developmental paediatrician
- Young adults with HH have complex management requirements that are best supported using a multidisciplinary approach
- The move from paediatric to adult services may be a challenging time for adolescents transitioning to self-management and support at school and university

Care Quality Commission and Department of Health

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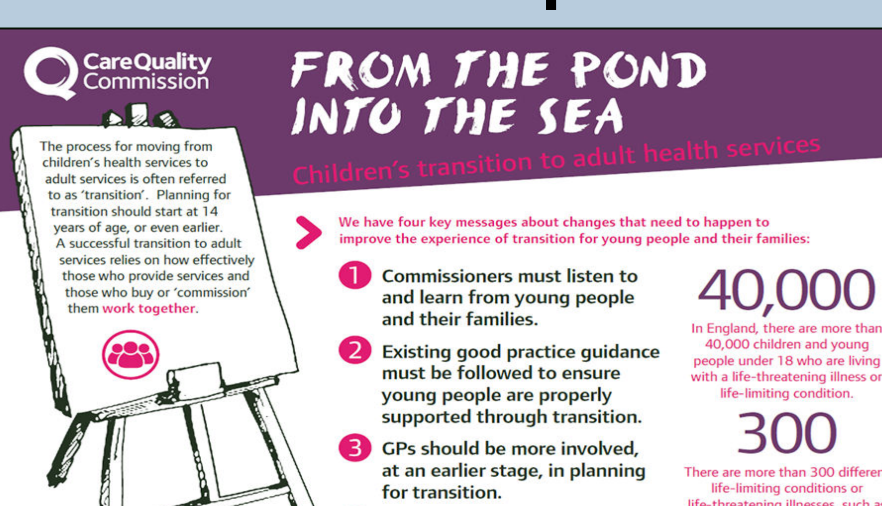


4 Adolescence/young adulthood should be recognised across the health service as an important developmental phase.

There are more than 300 different life-limiting conditions or life-threatening illnesses, such as cystic fibrosis, muscular dystrophy, severe cerebral palsy and certain types of cancer.

Health passports should be used more widely

Lead professionals should support young people and their families through transition

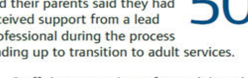
Parents' needs as carers should be assessed and addressed

Funding responsibility should be agreed early in the process

As part of our review, we spoke to 180 young people, or parents of young people, between the ages of 14 and 25 with complex health needs. This is what we found:

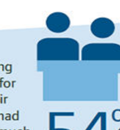
"From the pond, you are picked up and put in to the sea"

80% of pre-transition case notes reviewed (age 14 to 18) had no transition plans for health at all.



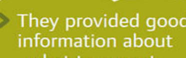
Only 50% of young people and their parents said they had received support from a lead professional during the process leading up to transition to adult services. **50%**

Staff that we spoke to from adult and children's services also had concerns about the support they were able to provide to young people during the planning for transition.



Only 54% of young people preparing for transition and their families felt they had been involved as much as they wanted to be. **54%**

We found that examples of where transition planning worked well were often in specialist services such as, teams specialising in cystic fibrosis, epilepsy, and cardiac services. These services had some common characteristics:



- They provided good information about what to expect.
- There was good communication with young people, their parents, and each other.
- They provided adolescent clinics (adolescence is defined as ages 10 to 19).
- The staff were consistent, and knew about the conditions and the young person's history.

Transitional Care

- Getting it right for children and young people (Sir Ian Kennedy 2010)
- Commissioning a good child health service (RCGP March 2013)
- Transition: getting it right for young people (DH 2006)

National Institute of Clinical Excellence (UK) Quality statements

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- **Statement 1** Young people who will move from children's to adults' services start planning their transition with health and social care practitioners by school year 9 (aged 13 to 14 years), or immediately if they enter children's services after school year 9.
- **Statement 2** Young people who will move from children's to adults' services have an annual meeting to review transition planning.
- **Statement 3** Young people who are moving from children's to adults' services have a named worker to coordinate care and support before, during and after transfer.
- **Statement 4** Young people who will move from children's to adults' services meet a practitioner from each adults' service they will move to before they transfer.
- **Statement 5** Young people who have moved from children's to adults' services but do not attend their first meeting or appointment are contacted by adults' services and given further opportunities to engage.

How?

- Team – Paediatric and adult HI specialists/Endocrinologists
- Psychologist
- Dietitian
- Nurse specialists

Patient & Parent/Carer

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- Parent 1: (AB)

AB has no hypo awareness. She has made gains in managing her condition independently but continues to need support. She needs to have direct access to expert nursing advice as she reduces her reliance on her parents.

We really needed support and advice from someone who really knows .. and who understands this complex and unstable condition. It has been very stressful, .. was unable to begin college until six weeks into the term due to the challenge of supporting her in college with her HI. The transition clinic would have been ideally placed to support with this.

Patient & Parent/Carer

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- Parent 2: (AC)

I feel it highly essential as a parent to know beforehand who will oversee AC in future and think the meetings and shared consultations vital to understanding the complexity of .. condition which differs highly from child to child. We as parents feel .. is being treated like a young adult who is slowly moving into looking at her own care and taking control over her future medical needs which is essential for her as she will be able to be somewhat independent in her medical needs.

Video

Barriers

- Barriers that prevent optimal self-management, including

1. heightened concerns about peer relationships and social interactions,
2. frustration and fatigue from the management of a chronic illness,
3. incomplete knowledge and understanding of chronic disease management,
4. inclination towards risk-taking and
5. difficulties in the transition to self-management.

- Transition clinics at GOSH and St Marys Hospital, Imperial College London

Aims of Transition clinics

In line with established NICE guidance

- Supporting education
- Empowering self-management
- Addressing parental and care-giver concern
- Addressing on-going medical issues
- Dealing with impaired awareness of hypoglycemia
- Providing advice around driving
- Providing support to higher educational institutions and those in employment
- Pre-conception genetic counseling, where appropriate
- Continued dietetic advice
- Alcohol and recreational drug advice

Medical issues encountered in adolescent and young adult patients with CHI

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Confirmed mutation causing CHI

- Symptom control
- Risk of diabetes
- Managing diabetes in non-pancreatectomized individuals
- Managing diabetes in pancreatectomized individuals
- Impaired hypoglycemia awareness

No mutation identified (in addition to above)

- Exploring a genetic diagnosis
- Counseling around diagnostic uncertainty

Developing transition pathways

Planning a service	Perform gap analysis	Involve young people in design of service	Ensure transition support is developmentally appropriate	Ensure transition support is strengths-based	Implement centered approach
Planning for transition	Timing appropriate	Named worker	Access to peer support	Building independence	Involve parents and carers
Before transition	Joint clinics with adult team	Multi-disciplinary team	Shared data with adult services	Outline services available	

Results

- 40 children in transition clinic >14 years
- Once a month clinic

A short survey was designed to obtain feedback on the transition clinic experience.

6 questions on 1 side of A4 that was completed by the young person and parent/carer.

Results

100% of young people and parents/carers found the transition clinics useful

What do you think we can improve???

"It was very hot in the room and with lots of people, I didn't know what to day"

"A bit more detail about what will happen once I leave here and go to St. Mary's"

"Give me a chance to meet other young people. A dietician is quite a good idea."

Young people and parent/carers felt that their expectations were met and received sufficient information about the clinic

We found dr shah and the team very willing and encouraging to allow EB a say in her medication and what her future medications may be . EB found dr Oliver very approachable and she is happy to move into his care once she reaches the age where it is appropriate to do so .

Outcomes

- Transition is hugely important with increasing needs of young people in complex conditions like CHI
- Clinic successfully running over 18 months
- Patient and Parent leaflet
- Patient Transition ePassport
- Information on GOSH CHI webpage
- Young Person forum

Thank you