

Development and implementation of a formal transition pathway for adolescents and young adults on home parenteral support in a UK intestinal failure unit

Angela Cole¹, Dr Sandhia Naik², Dr Michael Glynn¹, Minal Patel², Rebecca McConnell², Sarah Williams¹, Samreen Mailk¹, Jaini Shah², Carolyn Wheatley³ and Dr Shameer Mehta¹

1. Adult Intestinal Failure Team, The Royal London Hospital, Barts Health
2. Paediatric Intestinal Failure Team, The Royal London Hospital, Barts Health
3. PINNT patient charity



Introduction:

“Normal growth and long-term survival is now expected for most children and young people on HPN when only 10 years ago, the prognosis for survival was poor. Adolescents with IF now successfully transfer to adult services, many of which will have been dependent on PN since early infancy” (1).

A UK-wide survey of IF transition services (2015) highlighted the lack of clinical standards and the need for structured services to support adolescents and young adults (AYAs) through a vulnerable period of their lives (2). Despite this, there are no reports of IF transition models in the UK.

Aim:

To develop a structured transition pathway for adolescents and young adults on Home Parenteral Support to aid transfer to adult services.

Methodology:

- Development of a clinical pathway, led and implemented by the nursing team.
- Dedicated transition clinics attended by the paediatric and adult IF teams.
- Care proforma including clinical data and social history were developed to standardise consultations.
- Transition readiness tools for principle stakeholders (AYAs, parent/guardians, clinical teams) were developed in collaboration with the patient support group PINNT.
- Children suitable for transition and HPS independence training identified and pathway planned with homecare nurses.

Results:

- 2019**
- Dedicated annual transition clinics increased to six monthly clinics.
 - 15 young adults have progressed through the transition pathway.
 - The median HPS duration at transfer was 16.5 years (interquartile range 9-16.5 years).
 - 5 young adults have successfully transitioned to adult services (4 fully independent in PN care).
 - No episodes of catheter-related bloodstream infection, catheter thrombosis or IF related hospital admission occurred following a year post transition in any patient.
 - Clinic attendances were high; one patient missed one clinic within the first year in adult services (9% DNA).
 - All patients/parents and IF team members reported ‘very positive’ experiences throughout the transition clinics.
- 2024**



Feedback:

Health care professionals

- Refresher on “paediatric conditions”
- Feel good factor
- Better understanding on how services differ.
- Introducing the adult service to manage expectations.
- Knowing the social/family dynamics around the young person.
- An insight into support the young person may need (work, holidays, housing, education etc.)

Feedback:

Young people and Families

- “The first clinic felt like too many people, but the next time I went I could recognise people and it was easier”.
- Nice to know that both teams talk to each other, has helped to build trust.
- Knowing who is answering the phone when I need help.
- Safety Net.
- Mum’s tears of relief and thanks.
- Handshakes and familiar hello’s.

Conclusion:

A standardised transition pathway involving multidisciplinary paediatric and adult IF teams for AYAs on HPS is feasible and safe in the UK, and supports successful transfer to adult IF services. National guidance to standardise practice across accredited UK IF units is justified.

References

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