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## Conference on ‘Malnutrition matters’

### Symposium 6: Young people, artificial nutrition and transitional care Transition in young people on home parenteral nutrition

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Pharmacological, surgical and technological advances have resulted in children now surviving through adolescence into adulthood with conditions that were previously unseen by adult services. Arranging transition for young people on home parenteral nutrition (HPN) to the adult sector is one of greatest challenges for health services that care for young people. Transition is not only a key quality issue for health services, but is a multidimensional process covering psychosocial, educational and vocational aspects. Poorly-planned transition may result in difficulties when young people access adult specialist services. As a consequence, there may be increased risk of non-adherence or lack of follow-up, which carries dangers of morbidity and mortality as well as poor social and educational outcomes. Transition does not end at the exit from the paediatric clinic, but continues into the adult sector, which needs to provide developmentally-appropriate clinical care. Recent Department of Health initiatives are aimed at ensuring that young people do not miss out on healthcare during the transfer between paediatric and adult services. Transfer can be a major, often daunting, event for young people. Parents may also fear transfer and need to learn to ‘let go’ of some control, which may be particularly difficult with a young person on HPN.

#### **Intestinal failure: Home parenteral nutrition: Transition: Adolescent medicine**

During the last three to four decades use of parenteral nutrition (PN) has been successful in supporting survival and normal growth in paediatric patients with severe intestinal failure. Short-bowel syndrome, acquired as a result of extensive bowel resection, usually in the neonatal period, is the most common reason for intestinal failure<sup>(1)</sup>. Children receiving PN for primary digestive disorders, e.g. short-bowel syndrome and Crohn’s disease, may have a better probability of survival (89% after 5 years)<sup>(2,3)</sup> than adults (60% survival in adults)<sup>(4,5)</sup>.

Permanent intestinal failure also results from inherited conditions diagnosed in the neonatal period, which include severe motility disorders, such as chronic intestinal pseudo obstruction or long-segment Hirschsprung’s disease, and congenital enteropathies, such as microvillus inclusion disease and tufting enteropathy. Although these conditions carry a worse probability of survival than intestinal failure as a result of short-bowel syndrome<sup>(2,3)</sup>, and patients

are less likely to rehabilitate and stop home PN (HPN), children can now survive to adulthood<sup>(2,3,6)</sup>.

#### **Paediatric v. adult home parenteral nutrition**

The prevalence of paediatric HPN is estimated to be 2.2 per million of the general population<sup>(7)</sup>. While children with short-bowel syndrome have a better chance of weaning off PN than an adult with a comparable diagnosis<sup>(3)</sup>, it is estimated that in the UK up to thirty adolescents are poised to transfer to adult services over the next 5 years<sup>(7)</sup>. Many of these adolescents will have been dependent on PN since early infancy (PN for  $\leq 6000$  d). Of this cohort 40% have short-bowel syndrome secondary to neonatal causes, 30% have congenital enteropathies and a smaller number (15%) have severe motility problems<sup>(7)</sup>.

**Abbreviations:** HPN, home parenteral nutrition; PN, parenteral nutrition.

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**Table 1.** Key features of transition (based on Viner<sup>(16)</sup> and McDonagh *et al.*<sup>(40)</sup>\*)**Key features of transition**

- An active period of preparation, which occurs before and after the event of transfer
- Adapted to the young person's needs and views
- Is not distinct from the principles and practice of adolescent healthcare
- Starts early, approximately the age of 12 years
- Continues into adulthood

**Requirements for transition**

- A shared written policy between adult and paediatric providers, which has the young person's wider needs for the future at the centre
- An individual transition plan with education programme and goals to be reached by certain dates (Table 2)
- A nominated key worker, often a nurse specialist to involve the young individual in the planning process
- Independent visits; the importance of consulting with the young person alone, without their accompanying parents, is an important step towards building autonomy in healthcare. An opportunity should be provided for self confidence to navigate and negotiate services previously accessed by parents on their behalf and self-advocacy, and is one of main methods of demonstrating transition<sup>(44)</sup>
- Opportunity to meet the adult physician before transfer<sup>(33)</sup>
- Transfer to adult healthcare to be determined by the readiness of the young person and is usually after they have finished growth, puberty and school
- Transfer includes a comprehensive transfer of health information

\*WHO defines ages 10–20 years as adolescence and the Department of Health recognises that health services for young people cover those individuals aged 16–19 years<sup>(20)</sup>.

Linear growth may not always be completed by age 16–18 years when a patient might be poised to transfer to adult services, particularly if puberty is delayed. Adequate energy intake to allow a normal pubertal growth spurt is essential<sup>(8)</sup>. Requirements are assessed on an individual basis according to age and stage of growth, and a higher intake of intravenous fat than that required by an adult may be necessary to achieve adequate energy intake<sup>(9)</sup>. Flexibility in timing of transfer will ensure that the needs of individual young people are met. Children who miss out on development of oral feeding skills in the first year of life may have persistent eating problems that continue as young adults. Enteral intake may be reliant on gastrostomies or feeding tubes.

Intestinal failure-associated liver disease is more common in children (23% of patients receiving HPN)<sup>(2)</sup> than in adults on PN and carries a high mortality<sup>(2)</sup>. Key risk factors are preterm birth<sup>(10,11)</sup> and sepsis<sup>(12)</sup>. Difficulties placing catheters for venous access cannot be underestimated and require experts familiar with placing catheters in unconventional sites<sup>(13)</sup>. Intestinal transplantation has developed for those patients with complications of liver damage or loss of venous access, and children currently represent two-thirds of all candidates for intestinal transplantation<sup>(14,15)</sup>.

**Transition**

Preparing patients for transition involves more than simply describing future events and raising awareness of transfer<sup>(16)</sup>. Paediatric care is family centred, focusing as much on the parents as on the children. This approach provides poor preparation for moving to the adult sector. Adult health services assume that patients have an extent of autonomy and have the capacity to negotiate the healthcare system. Shift from parent-managed to self-managed care is required<sup>(17,18)</sup>.

The standard definition of transition is 'a purposeful, planned process that addresses the medical, psycho social and educational/vocational needs of adolescents and young

adults with chronic physical and medical conditions as they move from child-centred to adult-orientated health care systems'<sup>(19)</sup>. Key features of the transition are shown in Table 1.

**Adolescent medicine**

Young people (the WHO defines ages 10–20 years as adolescence and the Department of Health recognises that health services for young people cover those individuals aged 16–19 years<sup>(20)</sup>) are new independent users of health services. Provision of confidential healthcare that allows engagement with young people and promotes disease self-management behaviour (e.g. central line care) and engagement with the new HPN team is pivotal<sup>(21)</sup>. Screening for health risk behaviours (mental health, diet, exercise, cardiovascular risk, smoking) is as important in adolescents on HPN as in other young people in the population<sup>(22)</sup>. Opportunities exist for promoting health, disease knowledge and prevention (e.g. osteoporosis). There is growing evidence that skills training for young people with chronic illness can be associated with positive outcomes (e.g. improved information seeking, social competence and behaviour), which can maximise functioning and potential<sup>(23,24)</sup>. There have been several reports of increased unemployment in young adults that is not always related to their disability or educational achievement<sup>(25)</sup>.

**Benefits of transition**

Why is the transfer of healthcare so important? At worst, if it is not handled well, failure to engage with adult tertiary services makes routine clinic attendance less likely and quality of care may decline<sup>(26)</sup>. Young people who have experienced skills training in transition programmes and secure a strong relationship with the new healthcare team have better adherence to follow-up, improved disease control and quality of life<sup>(27)</sup>.

**Table 2.** Transitions undergone by the young person\*

Health transitions	Independent visits and phone calls, contacting the team, self care of the central venous line and setting up PN PN prescription New contacts, e.g. pharmacy, supplier or home-care company Dry goods and pumps Stoma care
Generic health issues	Health and lifestyle, exercise, understanding of adult-onset diseases (e.g. osteoporosis), sexual health, smoking, alcohol, narcotics and illegal drugs, self-esteem and body image
Home and psychosocial transitions	Self advocacy, knowledge of benefits, sources of support, peer support groups e.g. PINNT (which supports patients on intravenous and nasogastric nutrition)
Educational and vocational transitions	Work experience, moving away to college or university, career plans, financial planning, impact of disclosure of condition

PN, parenteral nutrition.

\*The Department of Health recognises that health services for young people cover those individuals aged 16–19 years<sup>(20)</sup>.

### Challenges: young people

While the young person with a chronic medical condition may have outgrown the paediatric healthcare environment, they may have delayed psychosocial milestones, reduced independence, social isolation and increased educational and vocational difficulties<sup>(28)</sup>. Management tasks may present greater obstacles and be more problematic in young people. Skill acquisition, e.g. setting up their own HPN, is variable and can be delayed in the context of chronic illness and be more problematic in young people as psychosocial milestones such as cognitive maturity and autonomy have not yet been achieved<sup>(29)</sup>.

Medical care might be rejected by adolescents as part of separation from parental control. They may be more prone to risk taking<sup>(29,30)</sup> or overwhelmed by the burden of healthcare issues and inappropriate expectations of clinicians.

Depression and anxiety are common problems in the daily life of adults on HPN and may arise as a result of lack of freedom, limitations in social life and being dependent. Somatic problems, fatigue and sleep disturbance impact on economic dependency<sup>(31)</sup>. Quality of life is reduced in the presence of depression and narcotic dependency<sup>(32)</sup>. HPN teams should be familiar with these problems and facilitate psychosocial support and/or cognitive training.

### Challenges: parents

Families of young people on HPN may be overprotective and have difficulties with transition<sup>(33)</sup>, particularly if care appears discontinuous or they feel excluded. Demonstration that young people have developed independence in healthcare as well as other aspects of their lives allows parents (and their doctors) to 'let go'.

Having a child on HPN is associated with physical and social stresses. Feelings of social isolation, loneliness and depression are reported in parents<sup>(31,34)</sup>. Young people and their families may be concerned about a reduction in services following transfer and a lack of preparation for such differences. Home-care services may be negotiated to support children and their families with nursing support<sup>(32)</sup>,

and families may face a change of services with a change of provider as well as a new adult nutritional care team.

### Transition: how to do it

There have been a number of recent publications on how to provide quality services for adolescents during transition, including the *National Service Framework for Children, Young People and Maternity Services*<sup>(35)</sup> and the guidelines from the Royal College of Paediatrics and Child Health<sup>(36)</sup> and the Royal College of Nursing<sup>(37)</sup>. They have been reviewed in the Department of Health's recent guidance in *Transition: Getting it Right for Young People. Improving the Transition of Young People with Long Term Conditions from Children's to Adult Health Services*<sup>(38)</sup>. Focus groups of adolescents have been helpful in developing models of care in rheumatology<sup>(39)</sup>, with common themes emerging, e.g. need for multidisciplinary team, continuity and good coordination between professionals, clear sources of information, care that minimises the impact of the medical condition on their life and a less-formal environment. There is a need for information, and web sites devoted to health issues for adolescents are popular sources<sup>(30)</sup>.

### Planning

Health transitions are one part of the wider set of educational, family and social transitions that young people make. These transitions are outlined in Table 2.

### Conclusion

Transition is a key quality issue for the National Health Service<sup>(14)</sup>. It is vital that both paediatric and adult centres address the challenge to ensure transition is a well-managed active process that starts early and proceeds in a planned and purposeful way. Securing relationships for the young person with a new healthcare team can enhance his/her self reliance while at the same time continuing good medical care.

Effective transition is important not only in terms of the potential benefits to patients from increased satisfaction and decreased morbidity, but in terms of the cost savings to enhance participation in society when the transition team 'get it right'<sup>(16,21,40)</sup>. Young adult clinics or wards covering ages 18–24 years may help an adolescent's complete transition, are associated with improved quality of care and may cost no more to implement than an *ad hoc* approach<sup>(41,42)</sup>.

Despite initiatives and evidence, progress in developing transition programmes in some medical specialities has been slow. A concerted effort is required to put recommendations into practice and for commissioning bodies to consider the resource implications for development of transition policies<sup>(30)</sup>. Knowledge and skills in adolescent medicine and transition should become more firmly incorporated into training programmes for healthcare professionals<sup>(43)</sup>.

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