BAPEN
Putting patients at the centre of good nutritional care

Top Tips for the Transition of Adolescent and Young Persons on Home Parenteral Nutrition

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Key points

1. Transition is not the same as transfer. Transfer refers to the 'handing over' of care from paediatric to adult services and transition to the gradual development of independence for adolescents and young persons (AYP).
2. There is no definite age at which to start or finish transition (usual range 14-23 years). The young person should be involved in the choice of adult centre.
3. The goals of transition should be clearly stated and involve paediatric, community and future adult teams, with the AYP having the central role. The goals depend on the AYP healthcare, educational/vocational and psychosocial needs. These goals may evolve with time.
4. The main healthcare goal should be the encouragement of independence and self-management in the administration of home parenteral nutrition (HPN), medications and underlying illness.
5. A key worker should be identified to support the young person during the transition period.
6. Post transition, involvement with the paediatric centre is encouraged and is particularly helpful for rare diseases.

Explanations

1. Some centres may view transition as merely the transfer of patients from paediatric to adult services; however, transition is not the same as transfer. Transfer refers to the handing over of medical care of the AYP from paediatric/adolescent care to adult services. Although this is necessary for the demarcation of service provision, this only covers one aspect of transition. Transition refers to the gradual development of independence and autonomy for each AYP. It often coincides with one of the most challenging times in a person's life. The AYP will be progressing through the developmental changes of puberty, including psychosexual development, as well as tackling important educational hurdles. As such, transition needs to be a planned and gradual process. A young person dependant on HPN will have this as an additional burden. This extra difference can be very pertinent at this challenging time, when peer influence is so important.

2. The transition process can start as early as 12 years old depending upon the patient/parents/carers and may continue after the transfer of care into adult services. The patient should be at the centre all decisions. Ideally, a written policy should exist between the adult and paediatric providers. Adult services should have comprehensive and detailed health information about each young person in advance of their transfer. The choice of adult centre may be helped by the AYP making an exploratory visit to a HPN designated unit deemed to be the most appropriate care setting for their specialist needs. The parents/carers need to be supported through the transition and realise that their contribution to consultations (even being present) is likely to reduce.

3/4. The paediatric and community teams should identify the adolescents suitable for transition and direct them to a dedicated transition service. Dedicated time (both in and out of transition clinics) should be allocated for discussions with the paediatric and adult teams, allowing the adolescent to self-direct their own goals for transition. These goals will be unique to every individual. This discussion can be revisited many times. The aims and goals can change, but promotion of independence should be repeatedly emphasised. All involved parties should make clear their expectations for the transitioning AYP.
A multidisciplinary transition clinic of about 45 minutes occurring at least annually may be suffice. Adult teams need to be sensitive to the fact that some AYPs are ready and able to take over responsibility for all of their own care, but some still need and value quite close parental/family support, even if adult teams expect to deal directly with the patient most of the time.

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The patient specific goals of transition can be subdivided as described below. Each aspect may evolve with time.

a. **Healthcare needs:** HPN might have been started during infancy or early childhood with parents/guardians/carers being responsible for its administration for many years. The AYP may lack clarity and understanding about their medical condition. This needs to be fully explained and the need for HPN reinforced. A checklist of the practical aspects should form part of the goals to promote independence. The practicalities may include: learning how to use infusion pumps; line care; administration of PN; medication dosing, frequency of administration and reordering prescriptions/feeds. The structure of adult HPN service needs to be made clear for the young persons and family/carers. There may be minor differences between paediatric and adult policies /procedures, which need to be explained/clarified. Often at the time of transition nutritional requirements may change (often reduce). In general, there should be few changes made to the ancillaries, including the pump unless there is a clear clinical need to do so. There may be many other aspects of the young person's complex underlying disease (e.g. progression, complications, etc.), which will need to be transitioned to other services (assuming that appropriate services are available for adults). The patient should be allowed to remain with the homecare provider they are currently with and have the same patient care co-ordinator. They should only 'transfer' care at a point of stability in their underlying disorder and HPN administration, in order for a smooth transition to adult services to occur.

b. **Educational/vocational needs:** Transition period may span important exams or coincide with a time when vocational decisions need to be made. The transition discussions with the AYP should include how HPN may affect their lifestyle choices and how it will impact their parents/career and themselves. Each adolescent should be encouraged to achieve their full potential. Practical issues such as the choice of university may need to be discussed, especially if the AYP is not going to be independent with their own HPN and will need nursing provision. Early discussions about the practical aspects related to any move from home will enable all aspects of the patients care to be as coordinated as possible.

c. **Psychosocial needs:** A plan must be in place to address care routines and psychological support during the time of transition. Screening for risk-taking behaviours (e.g. drugs, smoking and drinking) and mental health concerns during the transition period should not be forgotten. Sexual health and contraception should also be discussed.

5. There should be an assigned key worker. This person should allow the AYP to express their views, share their worries and concerns, ensure that the AYP is progressing appropriately through the transition process and help to assess readiness for transfer. They will act as their advocate. In order to encourage further independence, this should not be the treating physician, a nutrition support team member, or a family member.

6. Communication between adult and paediatric centres post transfer of care is valuable, especially for a AYP with a rare disease with which the adult physician has little or no experience. It is vital that the adult centre is fully appraised of the patient's previous therapies, complications and investigations so as to facilitate a streamlined transfer of care. However, in the vast majority of cases, once the patient has been fully transitioned and transfer has occurred the adult team assumes full management responsibility.

Further reading

- NICE guidance (NG 43). Transition from children's to adults' services for young people using health or social care services. NICE 2016; www.nice.org.uk/guidance/ng43.
- Kyrana E, Beath SV, Gabe S, Small M, Hill S. BAPEN, BSPGHAN Nutrition Working Group. Current practices and experience of transition of young people on long term home parenteral nutrition (PN) to adult services - A perspective from specialist centres Clin Nutr ESPEN 2016; 14: 9-13.
- Kyrana E, Beath S, Small M, Gabe S, Macdonald S, Hill S. Please mind the gap, young people with intestinal failure need you! A joint BSPGHAN, BIFA and BAPEN survey of transition experiences between paediatrics and adult services for Home Parenteral Nutrition (HPN). Clin Nutr ESPEN. 2015; 10(5): e191.
- Angela Cole. Transition for young people with intestinal failure. The what, the why, the where and the how? PINNT 2019. Available from PINNT via: comms@pinnt.com.
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