

Transition for young people with intestinal failure

**Transition guide for parents and carers supporting
young people and home parenteral nutrition**

**By Angela Cole, Clinical Nutrition Specialist
for Children with intestinal failure**



PINNT

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Transition is a word that you will hear throughout your child's teenage years in many different places, for example, in hospital appointments, at GP appointments and at school. The word transition in the booklet refers to the shift that your child will make from a children's nutrition team to an adult's nutrition team.

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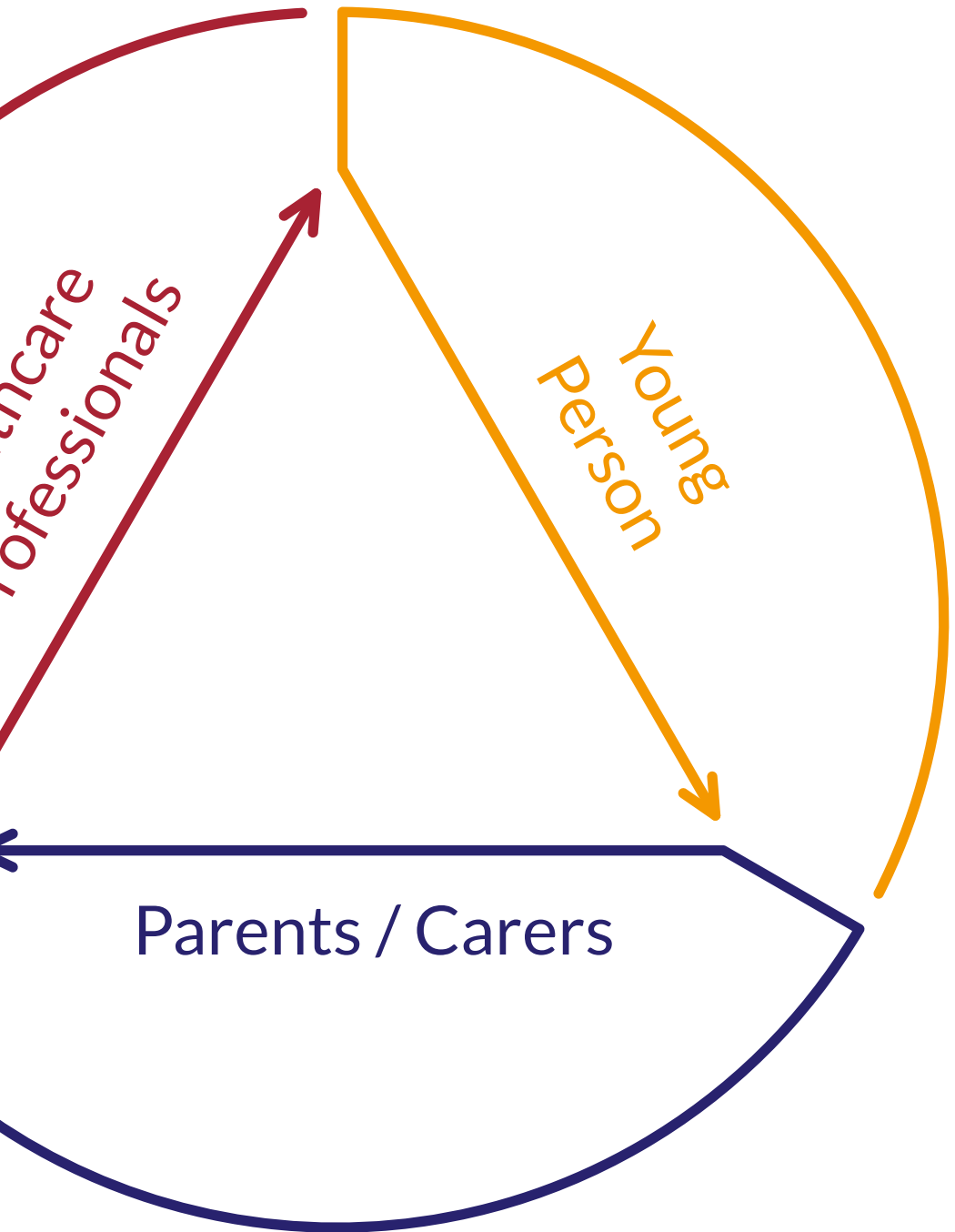
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Why does my child need to transition to an adult nutrition team?


The goal of transition is for your child to be engaged in the adult health care system allowing them to optimise health, maximise their potential in their chosen pathway and increase their quality of life. Transition is a pathway that requires planning and engagement from a triangle of care partners:

Good planning will help to ensure that you and your child know why transition is important, when transition will happen and where and how you will transition. You will have known the children's nutrition team for a long time and therefore it is understandable that both parents and young people may feel concerned about transition. However, with planning and information it can be a positive step.





What is Transition?



Children's nutrition teams are excellent at caring for children, but as your child grows into a young adult their health needs are likely to change. The most appropriate team with the relevant expertise, knowledge and services for adults needing home parenteral nutrition (HPN) are the adult nutrition teams.

It is sometimes hard to understand why transition needs to begin so early but it will become clearer and more relevant to you and your child as they start to mature. They may find different interests and to start to think about a career or further education, move out of home and start new relationships. As hard as this might be to imagine right now – it will happen!

This is your child's Transition pathway. Plans for your transition should be made with all of you, as part of the team - with your child becoming more interested in decision making and eventually taking control with the Nutrition team. You have known your Nutrition Team for a long time, it is understandable that you might feel sad and nervous about leaving them. By working as a team it is more likely that you will feel confident and happier about moving into adult services.

When does Transition start?

There is no exact time to start the transition pathway; however, there is a need to respond to the growing maturity of your child with intestinal failure. They need to become more involved in decisions affecting their own care and treatment. This should start as early as possible with the paediatric nutrition team and continue into adult nutrition care.

Your child's nutrition team will start to discuss the transition pathway when your child is around 12 years of age. They will travel the pathway with you until the adult nutrition team take over sometime between 16-18 years of age. might be to imagine right now – it will happen!



Where will my child's adult nutrition team be?

Your child's nutrition care will need to be established in a hospital that has an adult nutrition team with expertise in looking after patients needing HPN.

It may be that your child can transition to the adult nutrition team whilst remaining in the same hospital, but transition can also mean moving to a different hospital.

There are some key life choices that you and your child might want to consider whilst reviewing the right place for nutrition health care – for example, place of work, university location and travel arrangements.



Young people become more emotionally independent and want to make decisions for themselves – but they will continue to need your support – especially when making difficult decisions. It is understandable that you may feel unsure how to react at times – your opinions may be sought but disregarded – this happens to all parents as their children grow up but can be heightened when it is a healthcare decision.



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Remember that although your child might want you to step into the background at times, they may still want to talk to you whilst making the final decision themselves. Your relationship is part of the transition process. As hard as it may be to respect their views at times, this process will help build on the next steps of your adult relationship.



How will Transition happen?

Every hospital and nutrition team will have a different way to arrange the transition pathway. The PINNT Transition booklet for young people has a readiness for transition and independence questionnaire, this may be helpful for you to look at to provide pointers and highlight the areas that you and your child need to work towards over the years prior to moving to adult services.:

- Transition should always be a gradual process, with plenty of time for preparation and planning.
- You and your child should have a transition coordinator.
- There should be an overlap in care between children and adult services – this might be in the form of a joint clinic, where members from both the children and adult teams attend or it may be a young adult clinic.
- Your child should be encouraged to participate more at their outpatient appointments and eventually attend parts of it on their own.
- It is good practice for your child to be encouraged to start contacting their nutrition team independently while they are well – increasingly young adults prefer to use email, and this is okay.
- Support for your child in understanding clinical terms. As a parent/carer you will have had to learn lots of medical jargon and clinical skills. Working as a support network you and the nutrition team should help your child to understand these elements depending upon their ability and readiness.



It may be that your child can transition to the adult nutrition team whilst remaining in the same hospital, but transition can also mean moving to a different hospital. There are some key life choices that you and your child might want to consider whilst reviewing the right place for nutrition health care – for example, place of work, university location and travel arrangements.

Moving to an Adult Nutrition Team

Having the knowledge and the necessary skills to self-care is key to your child becoming as independent as possible and feeling in control, thus allowing them to realise their full potential.

For some young people their care and/or social development may be extremely complex, meaning that full independence is not planned at this point. However, everyone should have a transition plan that is developmentally and care appropriate.

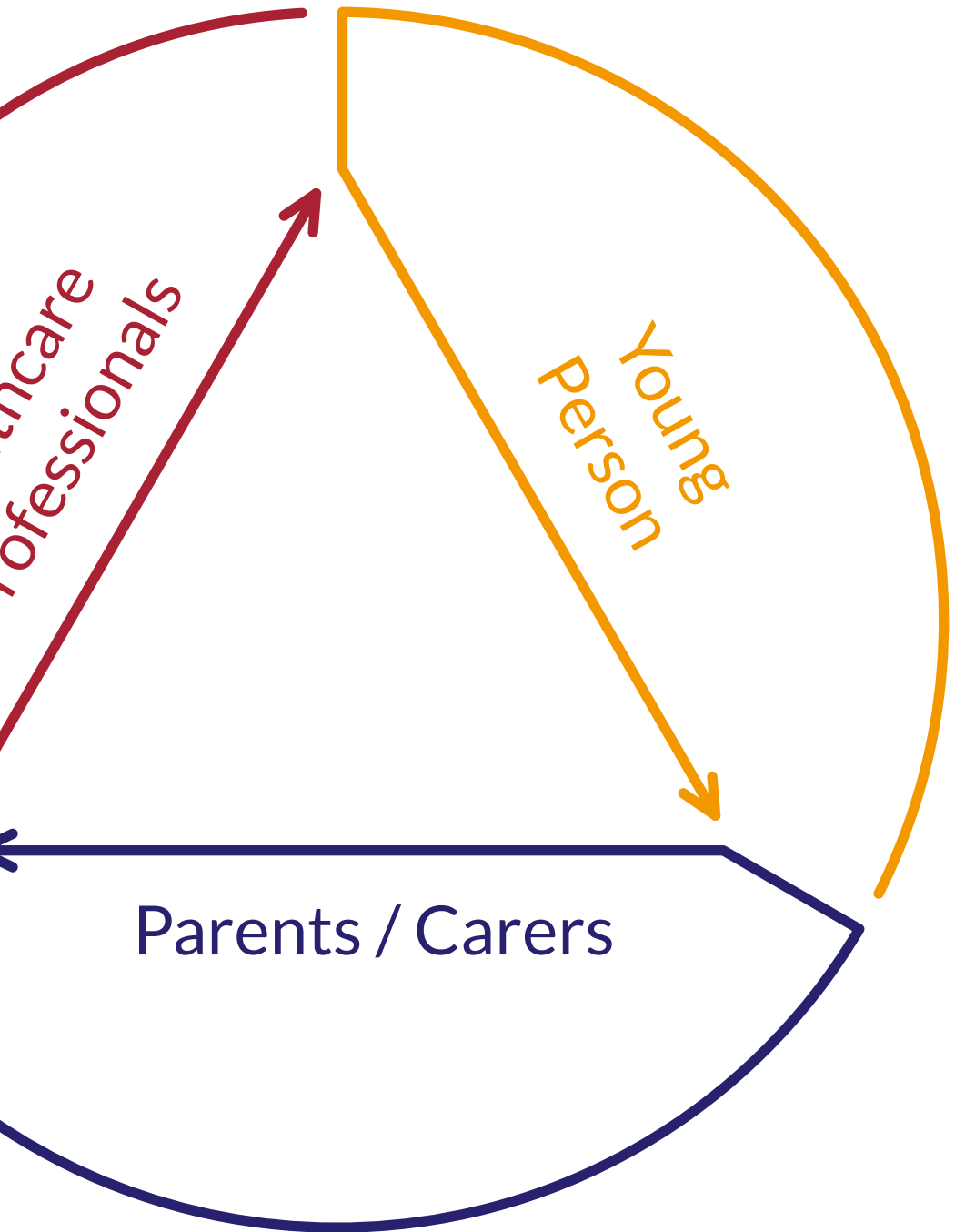
It is hard as a parent/carer when your child makes a decision that differs from yours. You may need support and reassurance through this time; it is important to discuss your concerns with your child and their nutrition team. Your child's nutrition team will need to respect confidentiality, but it does not mean that you cannot talk about your views. Re-visiting the paediatric team for advice is generally not a good idea; they no longer have direct input into your child's care and will not have access to all the relevant information to offer advice and make appropriate decisions.

Parents are almost always the people that young people turn to when they need help. It is important to maintain positive relationships so that the triangle of transition works as a team:

Maintaining this triangle may mean negotiating new roles within the triangle but each corner remains important during transition.



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Useful resources



Other books from this series:

- **Transition for young people with intestinal failure**
– **The what, the why, the where and the how?**
By Angela Cole, Clinical Nurse Specialist for Children with Intestinal Failure
- **Transition for young people with intestinal failure**
– **Information for Healthcare Professionals**

Suggest reading:

These are the documents

- <https://www.nice.org.uk/guidance/ng43>
- www.cqc.org.uk/sites/default/files/CQC_Trnsition%20Report_Summary_lores.pdf
- https://www.bsg.org.uk/resource/ayp_chronic_digestive_diseases_from_paediatric_to_adult_care.html

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