Transition for young people with intestinal failure

The What, the Why, the Where and the How?

By Angela Cole, Clinical Nurse Specialist in Nutrition Support
(Former Clinical Nurse Specialist for Children with Intestinal Failure)

UPDATED JULY 2024

PINNT

This booklet explains more about the transition services for young people with Intestinal Failure (IF) and Home Parenteral Nutrition (HPN). Living with Home Parenteral Nutrition is different for everyone and consequently the Transition process will also be different. Some young people feel nervous about this process, and some feel excited; we can't predict exactly what it will be like for you, but we can help you to get ready and feel as prepared as possible for Transition (moving from a Children's Nutrition Team to an Adult Nutrition Team).

Contents

What is Transition?

Why do I need to Transition?

When does Transition start?

Where will I need to move to?

How will the Transition happen?

THE PLAN

Contributors:

Angela Thompson – Roald Dahl Transition Nurse Specialist

National Paediatric Parenteral Nutrition Nurses Group

What is Transition?

Transition is a word that you might hear used in lots of places, for example, in your hospital clinic appointments, visits from the community children's nursing team, at you GP appointments and at school. The word transition is used to describe a shift from children to adult services.

Your Transition should be planned with your Nutrition Team. You might have lots of teams looking after you and it can be useful for everyone to think about your Transition and work together. Planning Transition with several teams can be challenging and it may be that a meeting with everyone proves helpful. Adequate planning will ensure that you know why Transition is important, when Transition will happen, where and how you will Transition.

This is your Transition pathway. Plans for your Transition should be made with you, as part of the 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.

Why do I need to Transition?

The Children's Nutrition Teams are excellent at caring for children, but as you get older your 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 might not feel like it yet, but as you get older you may also find that you prefer to be seen in a more grown-up environment. Adult Teams are very good at discussing things that may become more important to you as you get older – travelling, careers, moving out of home, sex and relationships, etc. You can also choose to discuss these things on your own, without your parents present.

When does Transition start?

There is no exact time to start the Transition pathway. However, your Nutrition Team should start to talk about and plan how Transition will work for you between the ages of 12 and 14 years.

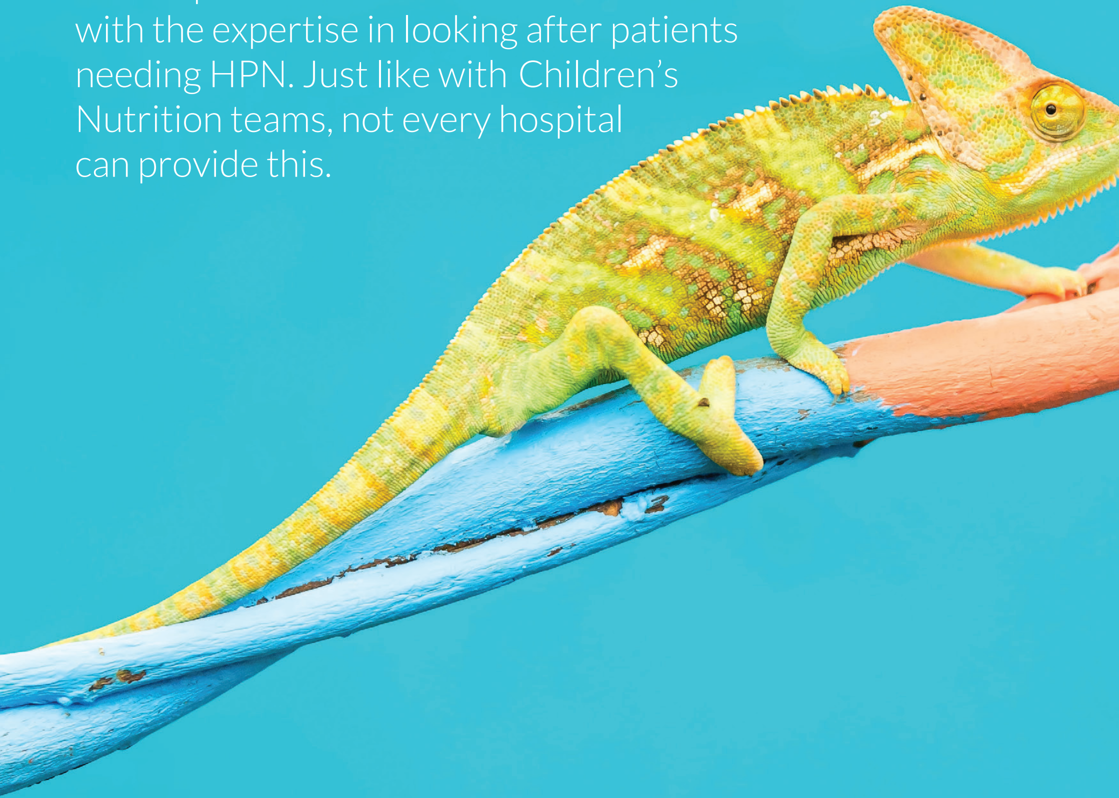
Transition is an on-going process, although discussions begin in your early teens the move into adult services will often happen between the ages of 16-18 years.

The exact age at which you move will depend on several factors as everybody is different. Your Nutrition Team will think about - and discuss with you - some of the factors that determine when you might move into adult services:

- How you (and your parents/carers) feel and when you think the best time to Transition would be. You know more than anyone what is going on in your life and when this move would fit best.
- How well you are. The best time to move into adult services is when you are feeling well and in control. Nobody likes to change when they are unwell.
- Are you still growing? Many Children's Nutrition Teams will prefer you to stay in their care until you have finished puberty or near enough. Children's Teams are best equipped to look after you until puberty is well on its way.
- How independent you are and how prepared you are to look after yourself. Independence and self-management will mean different things to everybody. Later in the booklet we will explore how you can prepare and build on these skills.

Where will I move to?

Your nutrition care will need to be established in a hospital that has an Adult Nutrition Team with the expertise in looking after patients needing HPN. Just like with Children's Nutrition teams, not every hospital can provide this.



It may be that you can Transition to the Adult Nutrition Teams whilst remaining in the same hospital, but Transition can also mean moving to a different hospital. It is important that you talk to your Nutrition Team and your parent/carers about what is important to you. Your choice may depend on where you are going to be working, if you plan on attending appointments on your own and how you will travel to the hospital or if you are thinking of going to university.

If you would like to visit other hospitals and Nutrition Teams, please talk to your Team; they might be able to help in arranging this.

How will Transition happen?

Every hospital and every Nutrition Team will have a different way to manage Transition, but every Transition pathway should have some things in common:

- **Transition should always be a gradual process, with plenty of time for preparation and planning.**
- **You should have a Transition Co-ordinator this is usually your nurse specialist.**
- **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.**
- **You might be encouraged to start contacting your Nutrition Team yourself, instead of your parents/carers. Many young adults prefer to email their Nutrition Team.**
- **You might start attending part of your outpatient clinic on your own. Your Nutrition Team will start to ask you questions directly and discuss things with you rather than with your parents/carers. It might be handy to start thinking about some questions that you would like to ask. You will find some examples and space to write your own questions at the back of the booklet.**
- **Transition is also a good time to think how you like to chat with your Nutrition Team. Some people prefer to email while others like to talk on the phone.**

Although Transition is all about you, it is important that we do not forget that this is a pathway for your parents/carers as well. Your parents/carers have spent years looking after you, and this will not stop, but they do have to adjust to handing responsibility over to you – this can be very hard for parents. Your Nutrition Team will help support them through the pathway along with you.

The Plan

When preparing for Transition, it is important to work out what you already know and what you need to know. Having the knowledge and the necessary skills to self-care is key to you becoming as independent as possible and feeling in control.

Your Nutrition Team will discuss – with you and your parents/carers – a teaching programme that will enable you to look after your central line, administer your parenteral nutrition and achieve independence. Sometimes this training will be facilitated by your Nutrition Nurse Specialist and sometimes by a home care company nurse (highly skilled in the care of central lines and parenteral nutrition).

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.

As well as learning the practical skills, it is important that you understand yourself and your body – for example, what operations you have had or what size your central line is. There are lots of tools and questionnaires that can help you and your Nutrition Team prepare and plan your Transition and teaching – your Nutrition Team may already have one that they use. We have designed some questions and key points that you might find useful to complete, so that you can start to take control. This will help your Nutrition Team build a plan that is made especially for you. You can find this at the end of the booklet as an insert.

Moving to an Adult Nutrition Team

Everyone in both the Children and Adult Nutrition Teams, recognise that Transition comes at a very busy and sometimes stressful time in life – exams, college, university applications, job interviews, relationships, sex, social life etc and that changing your Nutrition Team is the last thing you want. The good news is that your new Adult Nutrition Team will be better equipped to discuss how HPN fits in with adult life and how you can make the most of every opportunity – including plans to leave home and travel the world!

Tom's Story

I'm Tom, I've been on HPN since the age of two-and-a-half due to mesenteric cysts in my small intestine, leading to the majority of it being removed - I'm now the grand age of 38!

Transition is not something to fear. The major difference is that you are placed at the centre of the process as opposed to your parents/carers. You will be at the centre of all clinics/appointments and if any decisions are required it will be you who is expected to make them (alongside the professional advice of course).

You will become more responsible for your own care (something which I personally felt was important anyway – my parents had looked after me and had enough pressure on them for too long) ranging from taking care of your own stock levels and liaising with deliveries, to directly feeding back to the doctors/ nutritional nurses on any issues or concerns.

The level of care and support as you Transition is certainly still available if you require it and, personally, it was something that I felt was absolutely necessary to do in order to take responsibility for my overall care and grow into becoming an adult, no longer over reliant on my parents' support/care.

My personal mantra is to live life to the maximum wherever possible. I've always wanted to be 'normal', whatever that is. I work full-time and have progressed through my career with no special dispensation for my illness and with very few of my peers being aware of my condition.

I have always attempted to maintain a positive outlook on illness, and it doesn't impact me living a normal life. I regularly holiday abroad and, although it takes a lot of planning in advance, this is by no means a barrier that can't be overcome with preparation. I believe in being a responsible person who prepares and plans to cover all eventualities. Obviously, there is always the potential for the unexpected to happen, but let's be honest, everyone is subject to this. It's a case of juggling the normal with the unexpected and being prepared!

Transition and gaining independence have been key to me achieving and enjoying life.

Adil's Story

Embarking on the journey of learning to administer my own parenteral nutrition (PN) due to short bowel syndrome (SBS) was both a straightforward and empowering trip. It has been part of my life from a very young age. As a kid I barely paid any attention to it. However, not once did I think I would have to manage it myself one day.

Learning to manage my PN was not easy at all, but it was straightforward. It started with general safety training followed by having trainers assigned to me. Over several weeks these trainers came to my house when it was time to do my procedures, assisting me until I was competent to do my own. Although I was competent, I was supervised a few times to ensure I was confident to carry them out by myself. I had step-by-step procedures in a small folder for reference, along with other information relating to my treatment.

Transitioning to an adult clinic was one of the most daunting moments of my medical journey. These clinics played a crucial role in keeping me well and maintained from a medical point of view. Having been under the care of the paediatric team for many years, it was not easy to switch. Dealing with new people did not come easy to me.

Personally, I am very cautious and shy when it comes to interacting with others, including my doctors. However, one thing to note is that seeing familiar faces at the clinic does help a great deal. I cannot express the relief I felt when I saw a familiar face, my clinical nurse specialist, who was once in the paediatric team but now in my current adult team. Seeing a familiar face, and someone familiar with my history, made the journey much easier; I did not need to start again with a new person and felt able to communicate much more easily. I realise this is not the norm, but for me it was a great help.

Taking charge of my own PN care has significantly impacted my independence by not only improving my management skills but also my confidence and communication skills. Once upon a time I would have been terrified at the thought of doing my own PN care. During transitioning I found a way to overcome my biggest challenge – communication. I focused more on what I was doing rather than what I was saying. This made it a lot less stressful during the journey.

I had to learn to balance my studies with my PN. At first it was challenging, but over time it became easier. If I could go back and change one thing, I would have set reminders for relevant aspects of my PN treatment rather than needing reminders from someone else. Having a strong support network has been invaluable in my PN journey, especially when it comes to how easy the team are to communicate with.

> Without such support I doubt I would be where I am today. I cannot express how important it is to have support around you, especially with things such as doing your own PN, as this can be quite daunting at first.

For anyone learning to administer PN, I would advise that you take your time, there is no rush, and most importantly talk with the team around you if you are unsure or mistaken; feel no hesitation to ask your team.

Reflecting on my journey to administer my own PN I am amazed by how far I have come and the lessons I have learned along the way. Transitioning from a child who barely noticed what was going on with his health has been both challenging and rewarding.

One of the most significant obstacles for me when transitioning to adult clinics was the change; it was daunting, yet necessary for my continued good health. The familiarity of seeing my nutrition nurse provided immense comfort and eased the journey going forward. Her presence underscored the importance of familiar faces in the medical journey, making communication more accessible and fostering a sense of continuity in care.

Taking charge of my PN care has improved a few of my skills, as I've said, but has also boosted my self-confidence. The initial communication challenges I faced were significant, given my reserved nature. However, through this I learned to focus on the tasks at hand, reducing the stress associated with interactions.

Learning to manage my PN has been a transformative journey, marked by growth, independence, and the invaluable support of those around me. Despite the challenges I may have faced at the time, I truly believe it empowered me to take control of my health and face new responsibilities with confidence.

Questions, Questions, Questions!

You may have no questions or lots. We have put a Frequently Asked Questions list together – you might only want to ask some of them, one of them or none.

- **Do I have a Transition plan?**
- **Are there any young people that have already Transitioned into adult care that I can talk to?**
- **What do I need to know before I Transition into adult services?**
- **How might Intestinal Failure affect my future (education and jobs)?**
- **Will my condition affect my sex life and relationships?**
- **Is my fertility affected by my condition?**
- **Can I drink alcohol? What will happen if I drink alcohol?**
- **What will happen if I smoke?**

Below is space for you to put reminders for your own questions:

How well do you know yourself and where you are going?

Don’t fall off the cliff! Work as a team to build the skills and form relationships to climb the cliff together.

This is not a questionnaire that you are expected to answer ‘yes’ to everything. We want to know how we can support you in the Transition pathway. We may ask you to fill this questionnaire in many times so that we can see how the Transition pathway is working for you. You can fill this in on your own or with the help of your parents/carers or Nutrition Team. There may be things in the questionnaire that we have to plan more than others – everyone is different, we want to get it right for you.

All About You:	Yes	No, not yet	Someone needs to help me prepare for this/I will need help when I am in adult services – Who?
I know why I come to hospital to see the Nutrition Team. I know who my team are and what they do.			
I understand my condition and can describe it to others.			
I know what medicines I take (the name, what they do, how much and how often).			
I know who to call if I have any questions and who can support me.			

Me & My Home Parenteral Nutrition (HPN):

	Yes	No, not yet	Someone needs to help me prepare for this/I will need help when I am in adult services – Who?
I understand why I need HPN and my HPN plan (fat-free days, day off etc.).			
I know what I should do if my HPN is not delivered or is not available.			
I have had the chance to discuss the cautions of HPN and how I can help minimise the risks.			
I know the name of my HPN home care company.			
I understand how parenteral nutrition is made and how and when it arrives to my home.			
I am aware of the equipment that I need and how I order supplies.			
I know how to contact my home care company.			

Me & My Central Venous Device:

I know why I have a central venous device.			
I know what my central venous device is called and the size.			
I know what central venous device dressing that I use.			
I know what HPN administration pump I use.			

Me & My Enteral Feeding Device:

(Not everyone has one of these – if you are unsure chat to your Nutrition team or parent/carers)

	Yes	No, not yet	Someone needs to help me prepare for this/I will need help when I am in adult services – Who?
I know why I have an enteral feeding device/tube.			
I know what my enteral feeding device is called and the size.			
I know what my enteral feed is called and when I need to have it.			
I know what enteral administration pump I use.			
I know the name of my enteral feeding home care company and how to contact them.			

Clinics & Independence:

I am happy to ask and answer questions when I go to the HPN clinic.			
I contact my Nutrition Team by telephone or email by myself or would be happy to start.			
I understand the importance of my hand-held letter/passport and have been taught what to do in a central venous device or enteral device emergency.			

Looking After Myself:

	Yes	No, not yet	Someone needs to help me prepare for this/I will need help when I am in adult services – Who?
I have discussed with my parent/carers and Nutrition Team the process of learning my own HPN administration and care.			
I help my parents/carers get ready and observe the techniques used for safe administration of HPN.			
I feel comfortable to be on my own and that I would know what to do in an emergency.			

Lifestyle & Social Life:

I understand what steps I need to take to keep my central venous device safe during exercise.			
I understand how to prepare for a holiday and who to discuss this with.			
I am aware of my fluid and nutritional requirements, including what a healthy diet is for me.			
I have discussed the risks of alcohol, smoking and drugs to my health. I know who I can talk to if I want more information.			
I know that I can speak to my Nutrition Team for details on who to contact for sexual health advice.			

School & Leisure:

	Yes	No, not yet	Someone needs to help me prepare for this/I will need help when I am in adult services – Who?
I feel comfortable at school (homework and schoolwork, PE, residential trips and friends).			
I have started to think about what I want to do when I leave school.			
I am able to go out and see friends outside of school.			
I know how to talk to my friends about my medical condition – if I want to.			
I know who I can talk to if I am feeling sad or angry.			
I feel happy most of the time.			

PINNT

Suggested reading:

These are the documents:

- **Transition from children's to adults' services for young people using health or social care services, NICE guideline [NG43] Published: 24 February 2016:** www.nice.org.uk/guidance/ng43
- **From the pond into the sea. Care Quality Commission, Published 2014:** www.cqc.org.uk/sites/default/files/CQC_Transition%20Report_Summary_lores.pdf
- **Roald Dahl's Charity, Transition of Care:** www.roalddahlcharity.org/what-we-do/roald-dahl-nurses/transition-of-care/

Special thanks to Tom and Adil for sharing their story.

020 3004 6192
comms@pinnt.com
www.pinnt.com

Follow us on
Facebook/Twitter
@PINNTcharity

PO Box 3126, Christchurch, Dorset, BH23 2XS

Updated by **Designosaur.co.uk**