

# 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:

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.			
<b>Me &amp; My Central Venous Device:</b>			
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.			
<b>Clinics &amp; Independence:</b>			
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.			
<b>Lifestyle &amp; Social Life:</b>			
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.			





## 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](http://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](http://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/](http://www.roalddahlcharity.org/what-we-do/roald-dahl-nurses/transition-of-care/)

## Special thanks to Tom and Adil for sharing their story.

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