NHS
The Leeds Teaching Hospitals
NHS Trust

Transition from children's nutrition team to the adult intestinal failure (nutrition) team

FAQs

Information for patients

Abdominal Medicine and Surgery

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This booklet is to provide information on frequently asked questions (FAQs) for patients, their families and/or carers.

Moving from Children's to Adult Health Services

As you get older, your health care will eventually move from children's services (sometimes called paediatrics) to adult services. Most young people make this move just before their 18th birthday.

What is "Transition"?

Transition is the name for the process of getting you ready for this change.

It usually starts around age 14, so you've got plenty of time to learn, ask questions, and build confidence before the move to adult services.

Why does it matter?

The whole point of healthcare transition is to help you feel prepared, supported, and able to manage your health in the way that works best for you. By the time you move to adult services, we want you to feel confident talking about your condition, making decisions, and being involved in your own care and at a level that feels right for you.

Adult services can be different from children's services in a lot of ways and we want you to be prepared for that change.

Home parenteral (PN) Teenage Care Pathway

What age should the transition process start?

Transition usually starts in the early teenage years (often around 11-12) and continues until transfer to adult services, usually around 16- 18 years old.

What transition tools are used?

The paediatric team use the ready steady go documentation to help with the transition process. The team develop a bespoke bowel story to help with education.

How do I prepare personally for transition?

Transition is a gradual process that takes place over a number of years, and there are several things you can do to help prepare yourself. Start by learning about your condition and your care needs and try to take an active role in appointments by asking questions and sharing how you feel. Practising managing things like taking medications, booking appointments, and speaking up about your needs can help build confidence. It can also be helpful to talk openly with your parents or carers and the team about any worries you may have. Taking things step by step and asking for support when you need it is an important part of the process.

What if transition feels hard or overwhelming?

That's completely normal. You can talk to your nurse, doctor, or another member of the team. Extra support can be put in place if needed.

Who is involved with the transition process?

The transition process is a multidisciplinary approach, involving you, your family/carer, health professionals (from both children's and adult services). If required, you may have a complex transition nurse supporting you with the transition process so that it is as smooth as it can be. Everyone works together to make sure you feel supported and ready for the move.

Will I meet the adult team before the transition is completed?

Yes. You will usually meet members of the adult team before you move, so you know who they are and can ask questions.

Be rest assured that your new adult clinical team will know about your medical condition and will have contact with your paediatric team if required.

Can I look around the wards and clinic prior to the transition process?

Yes, we can book you in to look at our gastroenterology & surgical wards, our treatment room and the outpatient's clinic.

Will the team know my background/history?

Yes. Your full history is shared with the adult team before you transfer.

What if the young person has additional needs or disabilities?

If a young person has additional needs or disabilities, they will receive extra support to help make the transition as smooth as possible. Planning may take longer and involves the right professionals to meet their individual needs.

This may include the learning disability team, therapists, social workers, mental health teams, education staff, and specialist transition or keyworkers. Reasonable adjustments can be made for appointments, communication, and care to ensure the young person feels supported and understood. Parents and carers will continue to be closely involved, and decisions will be made at a pace that feels right for the young person.

Parents, carers consent & confidentiality

Will parents or carers still be involved?

Yes, parents can be involved if you would like them to be. If you don't want them to be involved the team can also support, you with this.

What happens to consent and confidentiality?

When you turn 16, the Mental Capacity Act applies. This means clinicians should assume you can make your own decisions unless there is a reason to think you cannot. You will be given support to help you make decisions. Your parents/carers can continue to support you and be involved in discussions about your care, where appropriate.

Contact information

Clinical concerns: 0113 206 8649
(Monday -Friday 08:00- 16:00) – Please leave a message and someone will get back to you.

Clinic appointments: 0113 206 8665
For any appointment queries

Out of hours: 0113 206 9191
J91 (Monday – Friday 16:00- 08:00 and all day/night weekends and bank holidays)

Email address: leedsth-tr.adultsifpatientenquiries@nhs.net
– Accessed Monday – Friday

People involved and team structure

Which professionals does the team consist of?

Our team consists of: Consultants (Gastroenterology & Surgical), Lead Professional, Doctors, Nutrition Fellow, Advanced Clinical Practitioner (ACP), Pharmacists, Nurse Specialists, Pharmacy, Assistant Practitioner & Co-Ordinator.

Will I have a named nurse?

No, you will not have a named nurse, but the team will work together to support your care.

If there are other specialities involved does the IF team take over all cares?

No, The IF team leads on intestinal failure–specific care (nutrition, PN, fluid/electrolyte balance, line management & IF related complications).

Clinic

How often will I be reviewed in clinic?

Dependent upon how often the consultant would like to review you will depend on the clinic review schedule. This maybe every 3/4/6 or 12 months.

How do clinics run?

Clinics run on a Tuesday afternoon and are split into various parts. You will attend clinic and have your weight taken and asked to do a urine sample by the clinic staff, you will then be seen by the dietetic assistant for your anthropometry(measurements), then you will be seen by the nurse who will check your line and ask a few questions regarding your PN administration and any issues you may have with your line. Lastly you will see the consultant for your clinic review, the consultant may see you with a dietitian and/or pharmacists as part of the clinic MDT.

Prescription

Does the PN prescription change immediately after transition?

Whilst in the transition process we may trial an 'adult' prescription, but at your first adult clinic appointment the team will reassess your:

- Nutritional requirements
- Weight and anthropometry
- Bloods
- Clinical goals

This may mean a change in prescription, and this will be communicated to you.

How are nutritional requirements different in adults?

Once your ideal adult body weight is achieved, prescriptions in adult services are designed to:

- Maintain body weight
- Prevent micronutrient deficiencies
- Minimise long term complications

Fluid management is controlled slightly differently in adults. Your prescription and fluid needs will not change on a daily basis. The prescription is designed to incorporate daily fluctuations in your fluid balance and volume are averaged. Any ad hoc additional fluid requirements can be managed with PRN bags of fluids.

Can PN be stopped after transition?

The duration of PN depends on the nature and stability of your condition. Any adjustments will be discussed at every clinic appointment.

Some patients may reduce or discontinue PN if:

- Oral or enteral absorption improves
- Surgical procedure restores intestinal function
- New therapies improve intestinal absorption
- **This should only occur under specialist supervision**

Can we use an octopus giving set on the adult wards?

Due to adult protocols, the adult wards are not trained in using octopus giving sets, whilst in the transition process, we will aim to try and phase this out.

Blood tests

How often will I have blood tests?

Blood tests will be done at clinic appointments, so this will depend upon when you are in clinic. If you contact us to say you are unwell with your line or PN, bloods will be done earlier.

Where are bloods done?

Bloods are done by the phlebotomists or nurses, bloods will be done in clinic (phlebotomy room in Lincoln wing clinic) and if required in our treatment room. Bloods are taken peripherally.

There are various phlebotomy rooms located thought Leeds teaching hospitals (St James, LGI, Seacroft & Wharfdale)

Do you give sedation for blood tests?

No, we do not give sedation for blood tests.

Do you use numbing cream?

We don't routinely provide numbing cream, but if you have some you can apply this before any blood tests.

Can bloods be done from my line?

Ideally, we would take bloods from your vein this is to prevent over accessing your line and prevention of any line infections, but if you have difficult venous access then we can take bloods from your line. Bloods are taken at each clinic as routine.

Treatment room

What is the treatment room used for?

The treatment room is used for: Line reviews, repairs and any clinical reviews if needed outside of your clinic appointment.

Central venous access device (CVAD) cares (Hickman/ Broviac line, PICC, Port a cath)

Do the nurses use aseptic non touch technique (ANTT) or full asepsis when accessing lines?

The nurses used ANTT when accessing your line, your children's team will prepare you for this change.

Do parents or patients need to be reassessed when they transition if doing own line cares?

We assess patients and/or their carers on an annual basis, to ensure safe practice as per the HPN framework.

Do you repair Broviac/Hickman lines?

Yes, we can repair vygon broviac hickman lines.

How quickly can you do a broviac/hickman line repair?

If you contact the team Monday – Friday (08:00- 16:00) we will aim to see you as soon as possible, this is time and staffing dependent and may not be on the same day.

Who inserts CVADs?

There is a team called the vascular access specialist team who specialises in the placement of lines. The team consists of: Consultant Anaesthetists, Anaesthesia Associates, Specialist Nurses, Peri-operative Specialist Practitioners and Senior Peri-operative Assistants.

If I need a new line what is the process? (Simple vs complex)

If you require a PICC or midline this will be done at the bedside by the VAST roaming team. If you require a removal or insertion of a hickman/broviac line or port-a cath this will be done in a theatre by the VAST team.

If you require a line via interventional radiology this will be done in the interventional radiology theatre.

Will the vascular access team get to know me before I transition from paediatrics to adults?

No, there is currently no service set up to get to know you prior to transition, but this maybe something that will be considered in the future.

Will the vascular access team(VAST) come and review me prior to having a hickman/broviac line or port insertion?

Yes, you will be seen by the anaesthetist prior to attending theatre, who will go through the procedure and get you to sign the consent form.

Enteral feeding tubes

What if I have a tube for feeding?

If you are not on PN but receive your nutrition support via a feeding tube e.g. gastrostomy or jejunostomy, you will also transition to your local home enteral feeding service. This will include a dietitian to monitor your weight and tolerance of feed who may wish to see you separately to the adult IF team, more locally to where you live, on a regular basis. They will be your first point of contact if you have any concerns about your weight or tolerance of feed.

What if I have a tube for feeding and I also have a line for PN?

If you receive both parenteral nutrition and tube feeding, the intestinal failure dietitian will manage both your enteral and parenteral nutrition and review this when you come to clinic. Similar to the Children's IF service.

What about practical issues with my feeding tube?

Instead of the children's community nurses, you will have access to feeding company nurses that work in the community in your local area and work closely with your adult home enteral feeding dietitian. They will be your first contact for any issues relating to your feeding tube or tube site.

If you have a more serious problem with your tube that requires medical attention at the hospital, you will have access to the adult enteral feeding nurse specialists at St James's Hospital within normal office hours. In the event of an emergency relating to your feeding tube, requiring urgent medical attention out of normal hours, you can contact the ward J91 and leave a message explaining that you are an Intestinal Failure patient that needs to speak to the gastro registrar about a problem with your tube. A doctor will call you back to assess you.

What if I have a tube that I use for venting but not feeding?

If you use a gastrostomy tube to vent air and fluid from your stomach but you do not feed through the tube, you will need to be referred to your local district nurses when you transition to adult services if it is the community nursing team that arrange your equipment for this and monitor or routinely change the tubes.

If your equipment for your venting tube is already provided by a feeding company, this is likely to continue and any practical issues with the tube would be dealt with as per previous FAQ above.

Care plans

Do you provide any plans?

We provide a written plan. Written plans state which bags to have on which days.

Do you provide any other plans, other than a written plan?

No, we don't provide any other plans.

Do you provide care plans for respite?

We can provide respite care with the written plan, but we do not do any other care plans.

Admissions – Ward/ Emergency care

What happens if I am unwell?

If you become unwell and need urgent medical attention, you should attend your local Emergency Department. If your symptoms are not urgent, you should contact your GP for advice. If your concerns are related to your PN or line, you can contact the specialist team for guidance as needed.

Will I have open access to a gastro ward?

No. In adult services there is no option for open access to a gastro ward.

Will I be admitted to the main bay on a ward?

You will be admitted to the main hospital bay, unless you require a side room.

Will a side room be available?

You will only be allocated a side room if you require one.

Will my parents/carer be able to stay with me throughout my admission?

We understand how important it is to have support from your parents or carer while you are in hospital. As you will be admitted to a ward, it may not always be possible for them to stay with you. Visiting and overnight arrangements can vary depending on the ward and clinical needs. The ward team will discuss what is possible with you and your family on admission and do their best to support you where they can.

What happens if I attend the emergency department?

You will be seen at reception and then triaged accordingly.

Treatment of CVAD infection (Line infection)

What is a line infection?

A line infection, also known as a catheter related blood stream infection (CRBSI) occurs when bacteria enter the blood stream through a CVAD used for PN.

What are the symptoms of line infection?

- Fever or chills/shivers (rigors) during or whilst infusing PN
- Feeling generally unwell
- Sometimes you may spike temperatures even when your line is not being used

What should I do if I think I have a line infection?

Stop the PN infusion (unless advised otherwise) seek urgent medical assessment.

What happens when I attend for a medical assessment

You should have:

- Paired cultures (peripheral and **ALL** CVAD lumens) need to be undertaken
- Commence on antibiotics
- Commence on a line lock (an antimicrobial instilled in all lumens)
- CVAD not to be used once paired cultures and line lock is administered
- Cannula for IV fluids in place of PN
- A midline request (this won't be done at an acute medical assessment; this will be done when you are admitted to a ward)

How do you treat a line infection?

If the CVAD can be salvaged, we would commence antibiotics and lock the line with the appropriate line lock. Duration would depend upon the type of infection.

Insert a midline - PN can go via a midline (this would be a hospital PN bag and not your home PN bag)

We will match your home PN script (electrolytes) as best we can using hospital PN and intravenous fluids

Can I continue receiving PN during treatment?

Yes, but we don't feed down infected lines, so we would request a midline insertion and administer PN via this.

What is a midline?

A midline (or midline catheter) is a long, thin, flexible tube inserted into a large vein in the upper arm

Why can't I have my own PN via a midline?

Due to the osmolarity (concentration) of the PN - We may not be able to use your home PN bags as the osmolarity may be too high.

Will my line need to be removed?

Not always, this will depend on:

- The infecting organism
- Severity of illness
- Response to treatment
- CVAD function

When must a line be removed?

- If the infection is an unsalvageable bug e.g. Staphylococcus aureus, Fungi, Pseudomonas
- If there is septic shock or persistent infection
- A failed line salvage (this is when we trial your line after the systemic antibiotic and line locks have finished)
- There is a tunnel CVAD infection

What antibiotics are used?

Initial treatment usually involves broad-spectrum intravenous antibiotics while awaiting culture results. Antibiotics are then adjusted according to the organism identified and its antibiotic susceptibility.

What is antibiotic lock therapy?

Antibiotic lock therapy involves instilling a highly concentrated antimicrobial solution into the line, this is instilled for a total of 10 days, but changed at day 7. It is often used alongside systemic antibiotics when catheter salvage is appropriate.

How long will treatment last?

Treatment duration depends on:

- The infecting organism.
- Whether the catheter is retained or removed.
- Presence of complications.

Uncomplicated infections commonly require 7–14 days of antibiotic therapy, although longer courses may be needed for organisms such as Staphylococcus aureus or pseudomonas infections.

How will I know the infection has cleared?

Treatment is considered successful when:

- Symptoms resolve.
- Blood cultures become negative.
- Inflammatory markers improve.
- The catheter functions normally (if retained).
- We may for some microorganisms carry out further imaging to ensure that there are no fungal or bacterial deposits to ensure the infection has cleared.

What happens if the infection returns?

Recurrent infections require reassessment to identify possible causes, including catheter damage, biofilm formation, poor catheter care, or an underlying source of infection. Catheter replacement may be necessary.

Can line infections be prevented?

Yes. Prevention includes:

- Strict hand hygiene.
- Aseptic catheter handling.
- Appropriate hub disinfection.
- Regular dressing changes.
- Proper catheter flushing and locking.
- Ongoing patient and caregiver education.
- Yearly refresher training if you are independent with your line care.

Can I manage a line infection at home?

No, all line infections must be managed in hospital

Will a line infection affect my long-term PN treatment?

Most patients recover fully with prompt treatment. However, repeated line infections can reduce available venous access sites (particularly if the lines need to be removed and reinserted) and increase the risk of complications, making infection prevention an important part of long-term PN care.

Exit site infections

What is an exit site infection?

An exit site infection is a bacterial inflammation at the exact point where the CVAD exits the skin.

What are symptoms of exit site infection?

Redness, swelling, pain or discharge at the exit site of the CVAD

How is an exit site infection treated?

We swab the exit site. If the swab comes back positive, you will be prescribed antibiotics. Sometimes an exit site infection is quite evident on inspection, and we will not always have to wait for the results before commencing you on antibiotics.

Equipment

What do I do if my pump stops working?

Contact your home care company to ask for a replacement pump.

Can I have a second pump?

Second pumps are only provided if your prescription requires two pumps.

Holidays

Can I go on holiday?

Yes, you can go on holiday, if you and your parent/carer are trained to give your infusions.

Do I need to provide you any information if I would like to go on holiday?

Yes. If you get in touch with us 8 weeks prior to going on holiday, we will send you a list of information we will need to be able to liaise with the home care company to supply your holiday script.

Can I take a spare pump on holiday?

Yes, we can ask the home care company to supply an extra pump for the duration of your holiday.

Lifestyle

Can I have a tattoo?

Yes, we have several patients with tattoos, we just ask that you make sure the tattoo parlour is clean and sterile.

Can I drink alcohol?

This should be discussed with the team as it may affect your nutrition, liver function, medications and hydration.

Can I smoke or vape?

Smoking and vaping are not recommended, as they can increase the risk of infection, affect healing and impact your overall health.

Can I exercise or play sports?

Yes, we encourage you to stay active, but to avoid activities that may pull or damage your line.

Can I work, go to college or university?

Yes. Many people work, go to college or university who have intestinal failure. Work/college or university should be able to make reasonable adjustments for you. The team can support with any supporting information if required.

Can I have sex or an intimate relationship?

Yes. Having a line or PN shouldn't stop you from having relationships. If you have any concerns, please speak to the team.

Can I get pregnant or have children in the future?

This is based on individual health and nutrition, if this is something you are considering please speak with the team as your nutritional requirements may change and you may need to be monitored more closely.



What did you think of your care?

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