

Learning to manage your HPN

Support and practical advice as you take on
more responsibility with your HPN care

Let's get started

Journal zone

Date:

Welcome!

This book is a space that's just for you. It will help you learn about your Parenteral Nutrition (PN) and prepare you to be more in control. Throughout this book, we'll refer to your treatment as PN.

Over the next few years, a lot might change. You might be thinking about school, exams, college, university, work or travel. You might also start to take more responsibility for your care, and meet new medical professionals.

This book is here to support you through these changes. It's packed with tips, tools, and space for your thoughts to help you feel more confident, more independent, and more you.

You're free to flip through the book in your own time, doodle, stick things in and come back to it whenever you like.

LloydsClinical

Contents

About you	4
The next step	5
Why do you need PN?	6
What is PN?	7
What's in your PN?	8
Your PN setup: The bags	10
When not to use your PN bags	12
Journal zone	13
Your prescriptions	14
Prescription example	16
Journal zone	17
Your line: The link to your nutrition	18
Line & bag safety, & your social life!	20
Growing up & taking charge	21
Telling others about your PN	22
School, friends & fun	23
Out & about: Your checklist	24
Safety basics: What to know & do	25
My happy moments	26

Journal zone	27
Learning to take the lead	28
My PN skills tracker	29
What happens when I call?	30
Getting ready to call	32
Journal zone	33
Challenges I've faced	34
Things that help me	36
Goals, dreams & big ideas	37
Building my future	38
My goals, my steps	39
My pledge to myself	40
To future me	41
Coming up: Adult care	42
Who I can contact for help	43
My essentials	44
Questions I have	46
Glossary	47

THIS BOOK BELONGS TO:

hello

About Me

Things I like:

Favourite song:

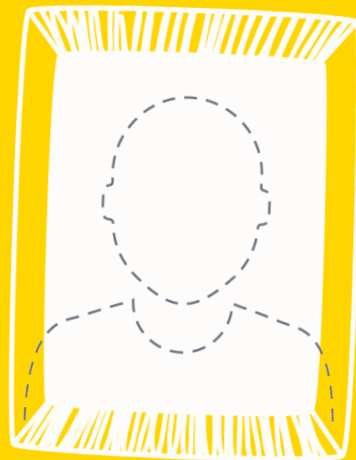
Favourite animal:

Favourite colour:

Favourite place to visit:

Favourite hobby or sport:

Favourite film or TV show:



Draw your self-portrait

3 words that describe me:

1

2

3



The next step:

Getting ready for what's ahead



Over the next few years, your care will start to 'transition'. This means you'll go from being looked after by the children's (paediatrics) team, to being supported by adult health teams. This can feel like a big change, and it's totally normal to feel nervous about it.

You'll be supported to learn new skills and take the lead in your own care, so that you feel ready for the transition. You'll feel more confident about your PN, and you'll have more freedom as you grow.



What you'll find in this book:

- Space to write down your questions, worries, goals and ideas
- Activities to help you work out what's important to you
- Tips for managing your line, PN, and routine
- Real-life stuff: travel, school, friendships, sleepovers, sport
- A helpful glossary with clear explanations of new words

Who's who in your care?

As you get older, you might start to meet new healthcare professionals, including doctors, dietitians, specialist nurses, and pharmacists. They are all here to support you.

You'll also get help from the Lloyds Clinical team. Lloyds Clinical may provide nurses who help you with your Parenteral Nutrition (PN) at home and support you as you become more independent. The decision about when Lloyds Clinical supports your care will come from your hospital team, and our focus is on helping you learn the practical skills you'll need day to day.

Your clinical team, friends, family and caregiver(s) are here to help you feel safe, confident and supported, and you can always speak up or ask for help if you need it.

Why do you need PN?

Your body is pretty amazing, but sometimes it needs a bit of support. That's where PN comes in. It gives your body the nutrients it needs through your bloodstream, instead of your gastrointestinal system.

PN is used when your body can't absorb enough nutrients from food. It's a way to keep your energy up, support growth, and help your body stay as strong and healthy as possible. Depending on your condition, you might only need it for a little while, or it might be part of a long-term plan.

You might need PN if your bowel:

- Is blocked
- Has a leak, perhaps from a fistula
- Is shortened or has been damaged
- Is affected by enteropathy, such as MVA (microvillous atrophy)
- Doesn't move food through the way it should (a motility problem)



If you know why you need PN, write it here

Why I need PN...

Not sure why you need PN?
That's okay – your hospital team can tell you.



Whatever the reason, your hospital team will have explained why you need PN and how long you might be on it for. If you have questions about your condition or treatment, your hospital Trust is the best place to ask. Lloyds Clinical nurses are also here to support you, especially with the practical side of your care. And remember, there's no such thing as a silly question. This is your health, and it's important that you feel confident in understanding what's happening.



There are loads of reasons someone might need PN, and no two journeys are exactly the same.

What is PN?

PN stands for Parenteral Nutrition. You might also come across other terms like Total Parenteral Nutrition (TPN), Home Parenteral Nutrition (HPN) or Home Parenteral Support (HPS). They all refer to the same thing - nutrition delivered straight into your bloodstream.

PN infusion bags are like your own custom energy pack. They're made up from your personalised prescription, tailored just for you with exactly the right mix of nutrients to give you energy and help you stay healthy.

Some people get all their nutrition through PN, while others can eat and drink, but still need PN because their body can't absorb enough from food alone. Either way, it's all about making sure your body gets what it needs.

It doesn't mean something's wrong with your body, it just needs a different kind of support.

What's in your PN?

Ever wondered what's actually in your PN bag? Here's a look at the nutrients inside, with information on how they help to keep you healthy.

Protein: Your body's building blocks

Think of protein as the stuff your body uses to build, grow and repair itself. Muscles? Yep. Skin? Definitely. Even your immune system needs protein to help fight off germs and reduce your chances of getting ill.

Quick facts:

- Your body uses protein to make new cells and fix damaged ones
- It helps you grow and get stronger
- In a typical diet, you'd get protein from meat, fish, eggs, tofu and beans

If your body isn't absorbing enough protein from food, your PN bag gives you what you need.

Fats: More than just fuel

Fats give you energy to study, exercise, grow, and have fun. They pack a punch, too - 1 gram of fat gives you 9 kcal of energy.

But your body also needs fat to:

- Protect important organs
- Keep your body temperature steady
- Help you absorb vitamins A, D, E and K
- Store energy for when you need it most

Vitamins: The small stuff that keeps you going

Vitamins are tiny but powerful nutrients that help your body make energy, keep your immune system in check, and support your metabolism (how your body uses fuel). You only need a small amount of each, and they come from lots of different foods, like the ones below.

VITAMIN	FOUND IN	WHAT IT HELPS WITH
A	Liver, dairy, colourful vegetables, yellow fruit	Healthy skin, vision, immune system
B	Wholegrains, meat, vegetables, peanuts	Energy production, brain function
C	Citrus fruit, peppers, broccoli	Immune support, helps absorb iron
D	Sunlight, oily fish, eggs	Strong bones, helps absorb calcium

Minerals: Small but mighty

Minerals are just as important as vitamins, even if they sound like something you'd dig up in science class. Your body only needs small amounts, but they do big jobs.

MINERAL	FOUND IN	WHAT IT HELPS WITH
Calcium	Milk, tinned fish, broccoli	Supports strong bones, teeth, and a healthy nervous system
Iron	Red meat, nuts, watercress	Red blood cell production
Potassium	Bananas, pulses, chicken	Keeps your muscles - including your heart - working well
Copper & Selenium	Wholegrains, seeds, seafood	Immune system support

Carbohydrates (sugars): Your energy boost

Carbohydrates, or "carbs", give your body the energy it needs every day. Whether you're hanging out with friends, going to school, or just chilling at home, carbs are what keep you going. 1 gram of carbs gives you 4 kcal of energy.

Your PN includes enough carbs to keep your body battery charged, even when food isn't an option.

Your PN setup:

The bags



As you get older, your PN bags might look different. That's totally normal – what's inside is still all about giving your body the nutrients it needs.

There are 2 main types of PN bags you might come across: **compounded bags** and **multi-chamber bags**. Here's what you need to know...

Compounded bags (aka made just for you)

Compounded bags are made up of individual ingredients personalised to you. Each bag is made especially for you by the Lloyds Clinical Aseptic Team – the people in lab coats who work in seriously sterile (super-clean) conditions.

Because they're tailored to you, the bags usually have to be kept in the fridge (between 2 and 8°C). Every bag also has a very strict use-by date. Some bags last for just 8 days, while others can keep for a month or more, depending on what's inside.

Top tips!

- Your PN bags have strict use-by dates – always check them before you use one.
- Before you take a bag out of the fridge, look at the dates on all the bags you have. Put the ones that expire (go off) soonest at the front, and those with the longest dates at the back. Keep rotating your fridge stock so nothing gets forgotten at the back!
- Always check the expiry date before using a bag. Each bag expires at 11:59pm (23:59) on the date printed. If you do your PN overnight, don't use a bag that expires that day. For example, if a bag expires on 01/01/2026, don't use that bag on the 1st January 2026 as it will expire while you're asleep!
- If anything is confusing, our delivery drivers and nurses can help you get organised.

Multi-chamber bags (aka cupboard heroes)

These bags are made in special factories under strict conditions. They don't need to be stored in the fridge. But they do still need to stay somewhere cool and dry, like a cupboard or drawer.

Before you use one, you'll need to roll and pop the chambers. Sometimes you may need to use more than one bag at once to get everything your body needs. It might sound complicated, but we'll show you what to do and you'll soon get the hang of it.

Multi-chamber Bag



If you're ever worried or feel confused, we're here to help.

It's always better to check than to guess - we're here to talk things through when you need to.

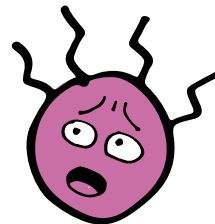
Compound Bag

When not to use your PN bags

Sometimes, it's a definite no when it comes to PN bags.
If you spot anything off, don't risk it.

Here's when to leave that bag well alone:

- The bag is leaking
- It looks damaged or odd
- It's gone past its expiry date
- You see bits floating in it
- The liquid looks a different or weird colour
- You're just not sure about it for any reason
- You think it's been stored at the wrong temperature
- If it's a refrigerated bag that's been out of the fridge for more than 24 hours



Basically, if it looks or feels wrong, don't use it.

Not sure?

Don't panic – our nurses, pharmacists and Patient Services are here to help and can quickly tell you whether your bag is safe to use or not.

Patients on Intravenous and Naso-gastric Nutrition Treatment



Did you know?

There's a special PINNT medical label you can add to your rucksack to help others understand how important your PN infusions are. You can find out more about that here: pinnt.com/Support/Medical-Tag.aspx

Journal zone

Date:

Whether you want to answer the questions or doodle how you feel, this space is yours to think and reflect.

Something I did that was brave, kind or helpful:

What I am happy about today:

What I am worried about today:

What would help me feel a bit better right now:

Wow

Draw an emoji that reflects how you're feeling today!



Today, I am grateful for...

Your prescriptions

Your prescription is one of the most important parts of your PN setup. It helps you, your hospital team, and your nurses know exactly what your body needs to stay healthy, so it's a good idea to familiarise yourself with it and check it regularly.

Your prescription, bags and PN routine are tailored to exactly what you need, and your team will support you as you learn how to use your bags.

Why does it matter?

Your prescription matters because it helps to keep you safe and well. Your Lloyds Clinical nurse will need to check your prescription every time before setting up the PN. This is to make sure the composition of the PN matches your prescription.

If you're unsure about anything, your Lloyds Clinical nurse can talk it through with you.

So, what is it?

Your prescription is written by your hospital team based on your individual needs. It includes the following information:

- A list of all the ingredients in your PN
- What type of PN bags you need
- When you need your PN (for example, how many days a week)



If you take any extra medicines, these will be on your prescription, too. You may take your medicines at the same time as your PN, and they will come with instructions for making them up and taking them. If you've got questions, you can always ask your hospital team.



How often will I need PN?

That depends on your body. Some people need PN every day, while others need it less often.

Your prescription will tell you how often you need PN – your hospital team will work this out for you. They also decide how long each infusion should last – it's different for everyone, but usually it's at least 12 hours.

How often you have PN, and how long the infusions take, can change as you get older, so it's good to keep track and stay informed.



Managing your pump

Once it's set up, your pump gives you the right amount of PN over the right amount of time. You (and your family/caregiver) will learn how to use the pump, and what to do if it beeps or an alarm goes off.

If anything goes wrong, don't worry. You or your family/caregiver can call Lloyds Clinical anytime and a nurse will talk you through exactly what to do to fix the problem.

Why your bags might be different

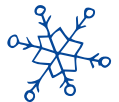
Your prescription might look different to someone else who has PN – some people have one combination bag at every infusion, while others have different bags on different days of the week.

Day or night?

You can have your PN overnight while you sleep, with your bag and pump on a stand next to you. If you have your PN in the day, pop it in a backpack and carry it with you wherever you go.

It's OK to have your PN during the day or night, but always check with your team first if you want to change it.

Remember, your PN bags might be:



- Refrigerated:
A compounded bag that's made just for you
- Stored at room temperature:
A multi-chamber bag that needs "popping" before use

Prescription example

Here is what your prescription will look like.

Don't forget the exact ingredients and how often you need to take it might be different to what is shown.



Paediatric Home Parental Nutrition Prescription

Patient Name: Stability Test(PT-267759)		Salford Royal NHS FT, , SALFORD, M6 8HD
NHS NO.:1234567891	Allergies: Paracetamol	
Date of Birth: 01/01/1969		
Patient Weight(kg): 50		Blueteq No.:
Address: Lloyds Clinical, Harlow, CM19 5GU		Lloyds Clinical

Parental Nutrition Solution Prescription

Please compound in a multilayer bag and administer intravenously						
Bag Code: IAMATEST25			Bag 1 of 1 RX_0001587			
Constituents	ML	Total Qty in Bag	Total Qty infused	Qty infused/kg		
SYNTHAMIN 17EF 500ML	500.0	Nitrogen 8.25 G	6.30 G	0.13	G/KG	
GLUCOSE 50% 500ML	675.0	Carbohydrates 337.50 G	257.63 G	5.15	G/KG	
SMOFLIPID 200MG/ML 500ML	500.0	Fat 100.00 G	76.34 G	1.53	G/KG	
CALCIUM CHLORIDE 14.7% 100ML	15.0	Volume 1,965.00 ML	1,500.00 ML	30.00	ML/KG	
POTASSIUM CHLORIDE 15% 100ML	10.0	Sodium 38.50 MMOL	29.39 MMOL	0.59	MMOL/KG	
SODIUM CHLORIDE 0.9% 250ML	250.0	Potassium 20.00 MMOL	15.27 MMOL	0.31	MMOL/KG	
NUTRYELT 10ML	10.0	Calcium 15.00 MMOL	11.45 MMOL	0.23	MMOL/KG	
NUTRATAIN	5.0	Magnesium 0.00 MMOL	0.00 MMOL	0.00	MMOL/KG	
		Phosphate (incl. lipid content) 7.50 MMOL	5.73 MMOL	0.11	MMOL/KG	
		Chloride 108.50 MMOL	82.82 MMOL	1.66	MMOL/KG	
		Acetate 41.00 MMOL	31.30 MMOL	0.63	MMOL/KG	
		Zinc 153.00 UMOL	116.79 UMOL	2.34	UMOL/KG	
		Selenium 0.90 UMOL	0.69 UMOL	0.01	UMOL/KG	
		Iron 18.00 UMOL	13.74 UMOL	0.27	UMOL/KG	
		Copper 4.70 UMOL	3.59 UMOL	0.07	UMOL/KG	
		Volume to be Infused 1,500.00 ML	30.00 ML			
		Min. Infusion Duration 12.00 HR				
		Infusion frequency 5.00 times/wk				
Stability: 21 Days @ 2 to 8 C		Stability ref: Internal		Osmolarity:		Chk:

Ancillary				
Drug Name	Dose / volume	Form	Directions/ Frequency	Max. per week/ total supply
I am a Test	10mL	PFS	TEST SCRIPT	x 5

Please supply the HPN feeds and medication, as stated above, repeated every 1-4 (as appropriate) weeks for 12 months from the date of this prescription, unless otherwise directed.			
	HCC Pharmacist	Screening Pharmacist	Prescriber
Print Name			
Signature			
Registration Number			
Date			

Journal zone

Date:

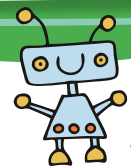
Whether you want to answer the questions or doodle how you feel, this space is yours to think and reflect.

Something I did that was brave, kind or helpful:

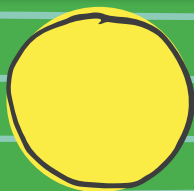
What I am happy about today:



What I am worried about today:



Draw an emoji that reflects how you're feeling today!



What would help me feel a bit better right now:

Today, I am grateful for...



Your line:

The link to your nutrition

Write down what matters to you. Your answers can help you feel more confident and prepared.

Your line is how your PN gets into your body. It's a soft tube that sits in one of your veins, with the tip positioned just above your heart. Sounds intense, but honestly, it's kind of genius. It means your body gets exactly what it needs, straight into where it can use it.

The type of line I have is called:

One thing I want to remember about looking after my line:

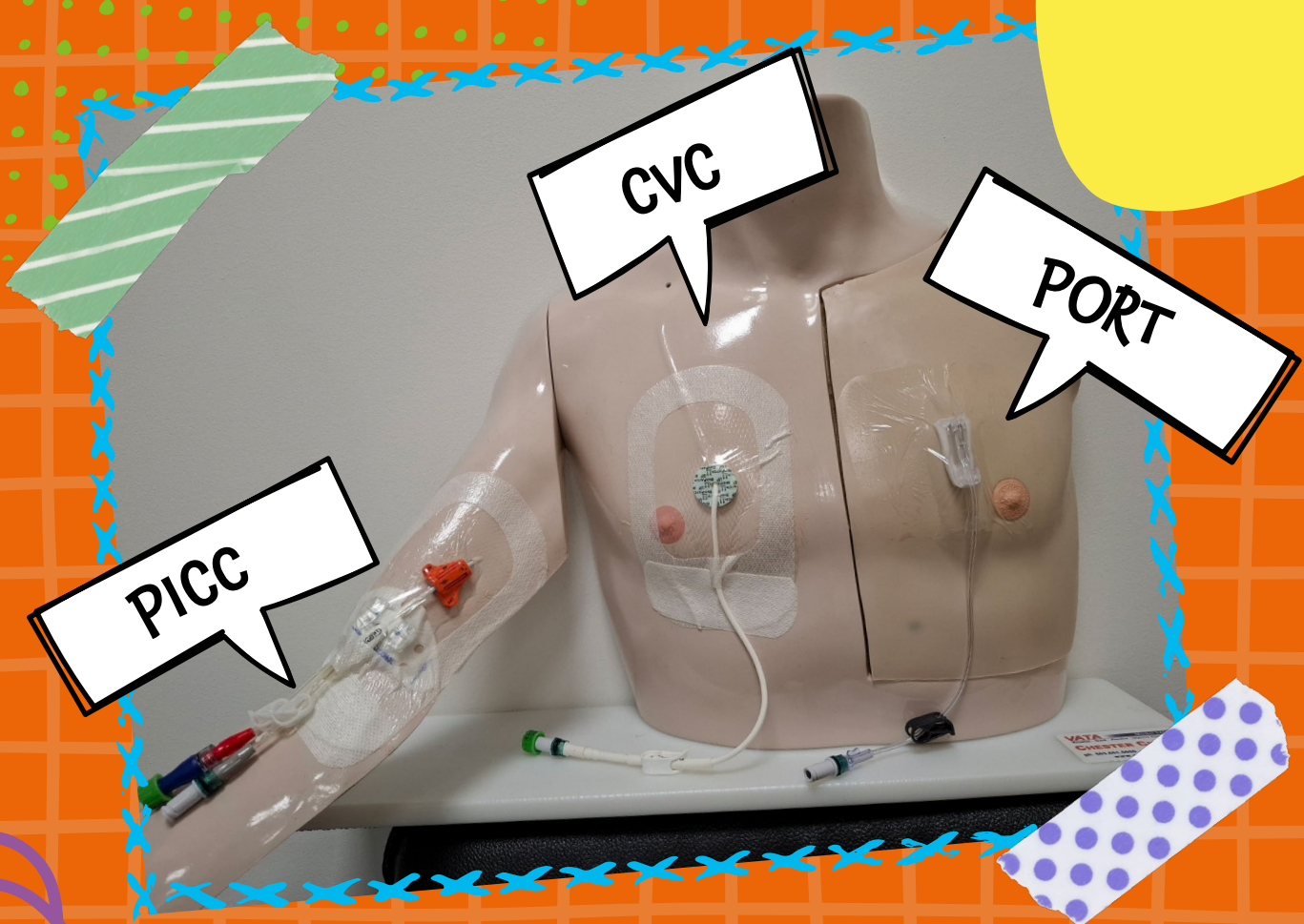
Something I've already learned to do on my own:

Something I'm a bit worried about:

What you need to know:

- Your line must stay in the right place. If you think it's moved or feels weird, tell your Lloyds Clinical nurse or hospital team straight away.
- Keep it clean and dry. It's okay to get messy, but your line dressing shouldn't. If it's wet, dirty, peeling, or starts to lift, it'll need changing.
- There are different types. You might have a PICC, CVC, PORT or even one with a brand name. Everyone's set up is a bit different – that's totally normal.

It might feel a bit strange at first, but your line is there to help you stay well, stay strong, and do more of the things you love.



Line & bag safety

& your social life!



The cool thing about PN is that you don't have to stay in hospital for ages. Learning how to manage your PN doesn't mean missing out – it means more freedom to do the things you love.

Being a teenager is the ideal time to start figuring out what works for you. It's your chance to build confidence, learn the ropes, and get comfortable managing things – ready for more independence when the time comes.



Real life, real possibilities



You might be thinking about:

- Going on a school trip
- Staying over at a friend's house
- Going to college or university
- Playing sports or joining a club
- Getting a job
- Travelling abroad



SUPER!!!

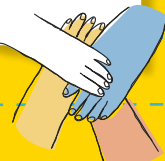
Good news!

Lots of people on PN do these things. It's totally normal to feel unsure about how to manage it all, but with a bit of planning, adjustments and some simple routines, you can stay safe and do the things you enjoy. Your Lloyds Clinical team can help you plan, so make sure you talk to them about what you would like to do.

Do What you Love



When you know how to take care of your line and your PN, it's easier to make PN fit around your life – not the other way around.



Growing up & taking charge

As you move towards adulthood, you'll take on more responsibility for your health. That means understanding your line, checking your bags, asking for help when you need it, and making safe decisions.

START TODAY



Once you've had your training and both you and your nurses feel confident, you can take the lead with your own care. That might mean doing everything yourself, or just the parts you feel ready for. **Either way, you're in control.**



You don't have to be perfect at it straight away!

If something's confusing or doesn't feel right, just ask your nurse or hospital team. That's what they're there for.

If you ever need additional support, that's OK too. Friends and family/caregiver can help, but they must be trained first to keep everything safe and clean.





Telling others about your PN

It's up to you how much you want to tell people about your PN. However, some people (like your teachers) may need a little more information on how they can support you. Remember, it's up to you what you say and to whom.

Write down some things you might tell your friends and family about your PN.

Write down some things you might tell your teachers about your PN.

Everyone handles health, independence, and talking about medical stuff differently. Some people like to explain every detail to their friends, others prefer to keep it low-key. **Choose what's right for you, you've got this!**

School, friends & fun

Handling school routines

- Let your teacher(s) or school nurse know about your line
- Create a plan for what happens if your line is pulled or you feel unwell
- Keep your safety kit with you at all times



Talking to teachers

- You don't have to explain everything, but giving them a heads-up means they can support you better
- Ask for help making adjustments in PE or on school trips, if needed

Answering friends' questions

- Some people will be curious, some won't even notice, but it's up to you how much you share
- Practise saying the following to see if either feels like something you'd be comfortable saying: *"It helps my body get the nutrition it needs"* or *"I've got a medical condition, but I'm all good"*



Going on trips or sleepovers

- Talk to your nurse about what to pack
- Make sure you've got spare supplies
- You might need to time your PN differently – it's OK, talk to your hospital team as there are options!

Being active

- You can still move your body – just safely
- Some sports might need to be swapped or adapted, like swimming, rugby, or other contact sports
- Your hospital team or Lloyds Clinical nurse can help you plan what's safe for you



Out & about: Your checklist

What to pack when you're out

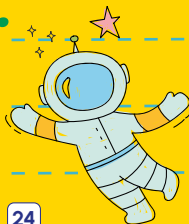
- ✓ Safety kit
- ✓ Hand sanitiser
- ✓ Spare dressing
- ✓ Your emergency contact info

Everyone's needs are different. Write your own list of essential items that you need to take with you.

Don't forget to include any extra supplies your team has recommended.

Write down questions you have about the things you might want to try or do.

Questions I have



Safety basics: What to know & do

✓ Check your dressing every day

It should be clean, dry, and stuck down properly. If it's lifting, damp, or looks off, tell your caregiver or the person that helps you with your dressing.

✓ Pack your safety kit

It's small, but super important. Always carry it in your bag, just in case something happens when you're out and about.

✓ Be aware of your line before sport or PE

Make sure your line is secured and covered. Let a teacher or coach know so they can help keep you safe. Watch out for accidental tugs or grabs.

You might need to adjust the way you play sports or do other activities to keep your line safe. Your clinical team can advise you on this.

✓ Don't ignore anything that seems odd

Pain, swelling, leaking, weird smells, bleeding – if something's not right, call your hospital team or Lloyds Clinical nurse. It's never a bother, they'd rather you call than risk something serious.

✓ Make a checklist

Plan ahead for trips, holidays, or sleepovers. Know what you need and leave enough time to pack without rushing.

✓ Create a schedule

Stick to your routine where you can, it'll help you feel more in control.

✓ Plan for the unexpected

Have a backup plan in case of fridge issues, schedule changes or anything else that might crop up.

✓ Keep asking questions

Talk to your Lloyds Clinical nurse if you're unsure how to manage PN in a new situation.

✓ Self-care

Be kind to yourself – rest is part of a full life, too.



My happy moments

Use this space to draw, write, or stick in photos of the things that make you feel happy, excited, or motivated.



Journal zone

Date:

Whether you want to answer the questions or doodle how you feel, this space is yours to think and reflect.

Something I did that was brave, kind or helpful:

What I am happy about today:



What I am worried about today:



POW

Draw an emoji that reflects how you're feeling today!



What would help me feel a bit better right now:



Today, I am grateful for...

Learning to take the lead

Keeping it clean: Your intro to ANTT

When you have PN, there's one technique you'll hear about a lot: ANTT or Aseptic Non-Touch Technique.

Sounds technical? It kind of is, but you'll get the hang of it. ANTT means not touching any of the important parts of your PN equipment. It's important, as it's part of preventing germs from accidentally getting into your body.

This matters because your line goes straight into your bloodstream, and if bacteria or germs get in, you could become very unwell. ANTT is what keeps your PN routine safe, clean, and free from infections.

As you get older, you might notice that your line is in an area that's private to you. Learning ANTT means you won't need someone else to access your line, and that's a big step towards independence.



You'll learn at your own pace

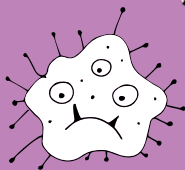
Your hospital team or Lloyds Clinical nurse will teach you ANTT step-by-step, with support. You might start by helping your nurse or caregiver with your PN, then gradually build confidence and take on more steps yourself.

It's your choice how quickly you take on each step. Some people want to take the lead right away, while others like to watch and build confidence first. Both are totally OK.

If you move hospitals, don't worry if they teach things slightly differently, their ANTT process will still be designed to keep you safe and healthy.

Remember!

- It's normal for different hospitals to do things differently
- No matter where you are, the process is always based on ANTT
- If you're ever unsure – ask!



My PN skills tracker

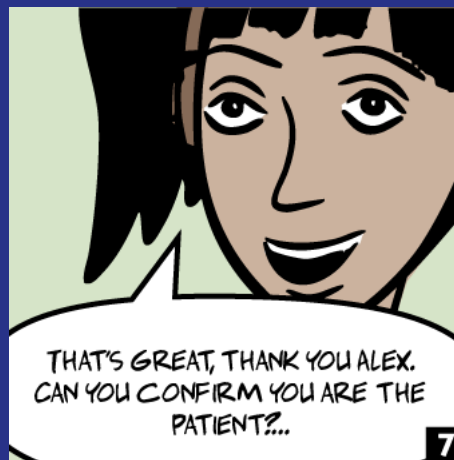
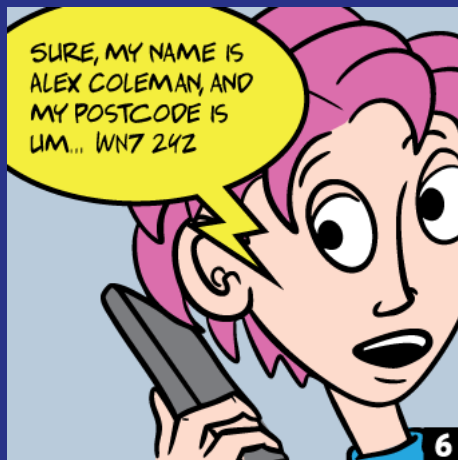
Use this section to track your progress, build confidence, and celebrate your wins – big or small! Don't forget to update your tracker as you improve over time.

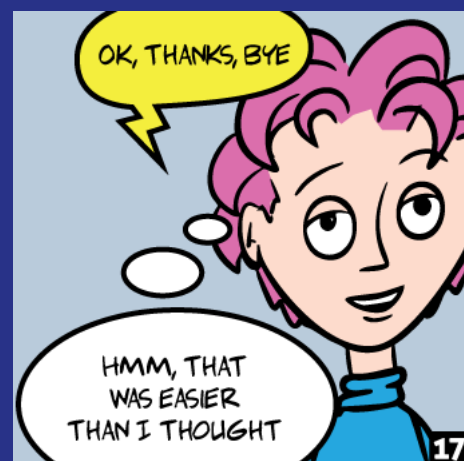
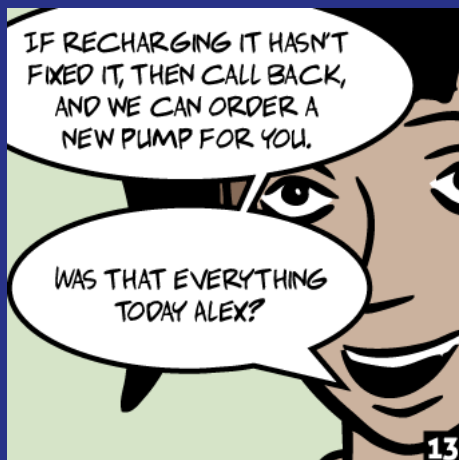
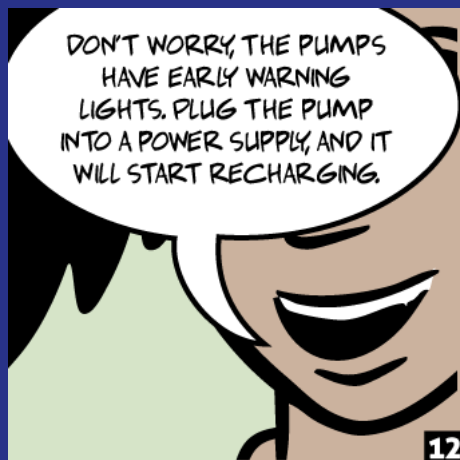
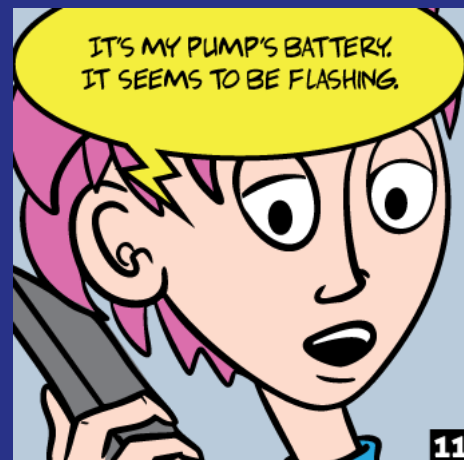
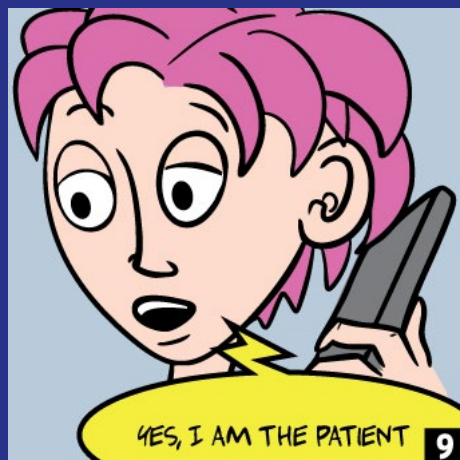
SKILLS	HOW CONFIDENT I FEEL ABOUT MY PN SKILLS			
	Not confident	A little confident	Confident	Very confident
Washing my hands like a pro				
Setting up my clean work surface				
Opening dressing packs the right way				
Spotting key parts of my equipment				
Keeping things sterile while I set up				
Storing my PN in the right place				
Recognising when something's not safe or clean				
Cleaning my line site				
Flushing my line				
Connecting my PN				
Disconnecting safely				
Staying calm when things don't go to plan				
Remembering all the steps				
Asking questions when I'm unsure				
Doing a safety check				
Changing the dressing				

What happens when I call?

Calling us might feel a bit daunting — but we're here to help.

There are lots of reasons you might need to get in touch, so don't be afraid to pick up the phone. Here is an example of a typical conversation...





Getting ready to call

When you call Lloyds Clinical, they'll ask a few questions first to make sure it's really you.

This helps protect your information — it's part of something called GDPR (General Data Protection Regulation). It just means your personal details are kept safe and only shared when they need to be.

What I want to say or ask:

Use this page to write down the key information you might need to share. You can also jot down any questions or reminders before you call, especially if you feel nervous or forget things when you're on the phone (totally normal!).

Name:

Date of birth:

Home address:

Postcode:

Phone number:



Got your info ready?



Take a deep breath — you've got this.



If you're not sure what to say, just start with "I need help with..."

Journal zone

Date:

Whether you want to answer the questions or doodle how you feel, this space is yours to think and reflect.

Something I did that was brave, kind or helpful:

What I am happy about today:

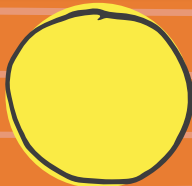


What I am worried about today:



What would help me feel a bit better right now:

Draw an emoji that reflects how you're feeling today!



Today, I am grateful for...



Challenges I've faced

Challenges can feel tough, frustrating, or just plain rubbish, but they don't last forever. As cheesy as it sounds, they are often part of learning and making progress.



Use this space to reflect on the hard stuff, recognise how you got through it, and think about what helped you along the way.

No Fear

What was hard?

How I handled it:

Next time I will...

What was hard?

How I handled it:

Next time I will...



OMG



COOL



What was hard?

How I handled it:

Next time I will...

What was hard?

How I handled it:

Next time I will...

What was hard?

How I handled it:

Next time I will...

What was hard?

How I handled it:

Next time I will...

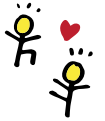
Things that help me

Everyone has different things that help when life feels overwhelming. This page is for you to explore what works for you – from small comforts like listening to music, to tools that help you feel calm, focused, and in control.

Create your own toolkit that you can refer to when you need to be reminded of things that make you feel good. Draw or write what would be in your toolkit.



Things that make me happy...



Things that make me feel better...

When I feel overwhelmed, I need to...



Things that keep me calm...



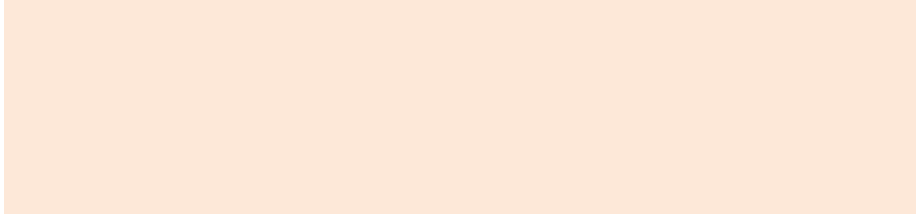
People and places I can turn to that make me feel better...



Goals, dreams & big ideas



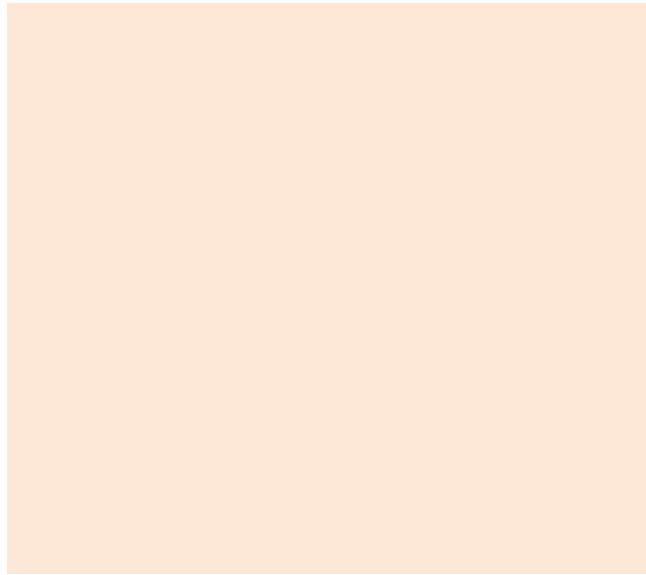
Things I want to try:



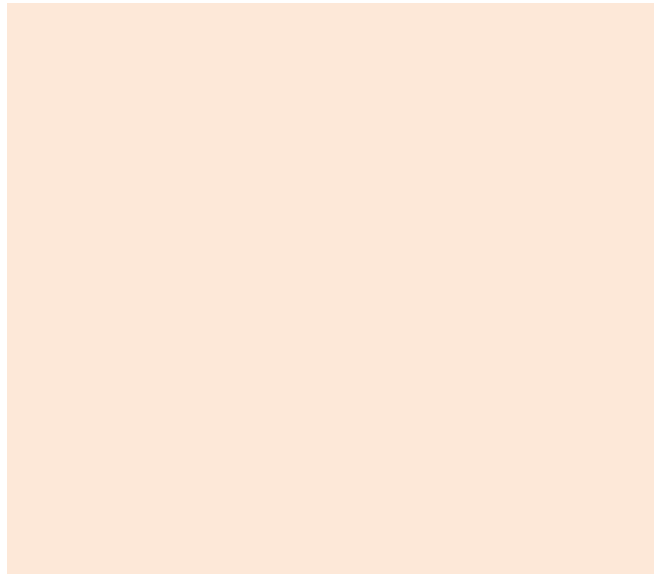
It's great to dream big,
even if you're not sure
how it will happen yet.
This page is your space
to think about any ideas,
goals, or experiences
you're curious to try.



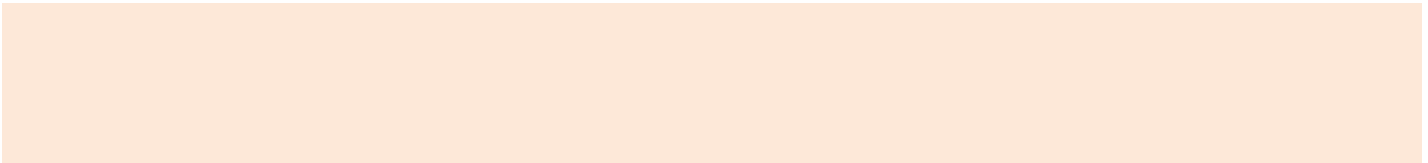
Places I want to go:



I want to get better at...



If I could do anything I would...



Building my future

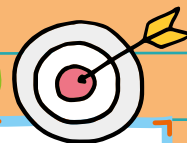
Life can get so busy that it's easy to just focus on getting through each day! But it's also important to take a moment to think about where you're heading.

This section helps you to explore what you'd really like to do, and turn those ideas and goals into real steps you can take, now and in the months ahead, to build the future you want.

And don't forget, you can look back at your **Goals, dreams & big ideas** page if you've already completed it — there might be an idea you want to build on.

Notes:

My BIG ambition!



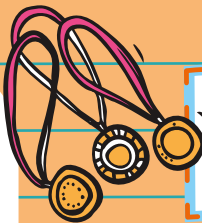
Choose one goal or dream that really matters to you, and use the prompts to explore why it's important and what might help you achieve it.

What I want to do most:

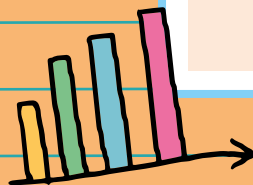
Why it matters to me:

What I'm good at that will help me get there:

What I might need help with:



IDEAS



My goals, my steps

Write down some of the things you'd like to do and how you're going to achieve them – no matter how big or small.

What I want to do	What I need to learn or do	Who can support me	When I want to do it	Notes
Travel around UK <div>Example</div>	Learn budgeting + travel research + managing my PN	My cousin who's travelled, nurses.	18 months	See if anyone else wants to come with me. Contact PINNT to see if they can give me some advice

My pledge to myself

A pledge is a promise to yourself. It could be something practical, like trying something new, or having a clear-out, or something more mindful, like going for regular walks or being kind to yourself on bad days.

Choose a few that feel right for you right now - you can always add more later.



You don't have to get everything right straight away, but pledging something to yourself can help you keep going.

I pledge to...

- Ask for help when I need it
- Take small steps even when things feel big
- Be kind to myself when I make mistakes

Examples



I pledge to...

A large, empty rectangular box for writing a pledge.

Imagine the kind of person you hope to be, what you'll be doing in the future, and write a letter to your future self.

You can include big dreams, small wins, things you're excited about, or even advice you think future-you might need.

Here are some questions to get you started:

- Where are you?
- What are you proud of?
- How are you spending your time?
- What's important to you?
- What goals do you want to have achieved?

To future me



Writing to your future self is a great way to check in with what matters to you now, and when you read it back later, it can remind you of how far you've come.

Coming up:

Adult care

As you get older, your care will move across from the children's (paediatric) team to an adult healthcare team. This can feel like a big change, but you won't be doing it alone.

Your new team will still be there to look after you and your PN, just like before. The difference is that you'll start taking more of the lead. You'll be included in decisions, asked for opinions, and encouraged to take charge of your care. Don't worry, you'll get plenty of support along the way.



Got questions?

Ask away! Seriously, there's no such thing as a silly question. Whether it's about your hospital, your PN, your nurses, or how something will work in the future – just ask. That's what we're here for.

How does it work?

- The transition usually starts around the age of 14, but it doesn't happen all at once. It can take months or even years to move over fully.
- Your hospital team will guide you through it step by step.
- Some adults who have infusions at home are not supported by our nursing team, but we are available by phone if you have any questions.
- If you already have Lloyds Clinical nurses helping you at home, they'll support you in moving over to our adult nursing team when the time is right.
- You won't lose support, you'll just have a new team that's focused on helping you move into adulthood with confidence.



Who I can contact for help

Use this page to write down important details like names, phone numbers, emails and websites.

Name	When should I contact them?	Email address	Phone number	Notes
Parenteral Nutrition Team	When I have questions about my PN or if I'm worried about something	-	0800 035 5678 or 0345 263 6123 0345 2636115	Monday to Friday 8.00am–6.00pm Out of hours

My essentials

When you're managing your own PN, there are some key things you'll need to know and do to keep everything running smoothly. These pages are your go-to guide for the everyday essentials, so you feel prepared, confident and in control.



Contact Lloyds Clinical if...

- Your fridge breaks or your bags have been left out
- Your pump isn't working properly
- You feel unwell or something just doesn't feel right
- A PN bag looks cloudy, has bits floating in it, or just looks weird
- You're running low on supplies
- You're going on a trip and need help planning
- You've missed a dose or made a mistake
- You have any questions or worries – literally, anything at all!



If I want to socialise, I need to make sure I...

- Have packed my safety kit
- Know where I can safely do my PN (i.e. at a friend's house)
- Let someone I trust know about my line (just in case)
- Plan my infusion times if I'm going out
- Know who to call if something doesn't go to plan



Do you know how to:

- ☐ Check the expiry date on your PN bag
- ☐ Store your bags safely (the fridge, or a cool, dry place)
- ☐ Set up and disconnect your PN using ANTT
- ☐ Spot if your line dressing needs changing
- ☐ Pack your safety kit for school, trips and sleepovers
- ☐ Respond to pump alarms or errors
- ☐ Organise your PN delivery and supplies
- ☐ Ask for help if something doesn't feel right
- ☐ Rotate stock in your fridge so older bags get used first
- ☐ Keep track of your infusion schedule

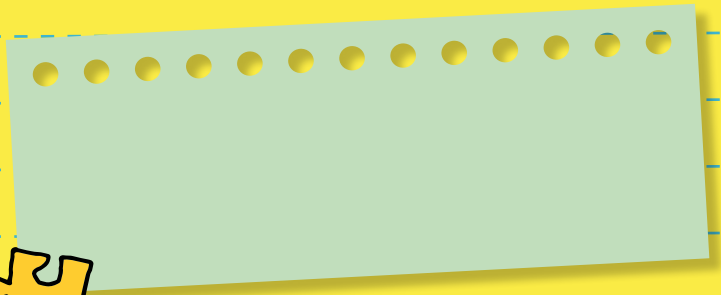
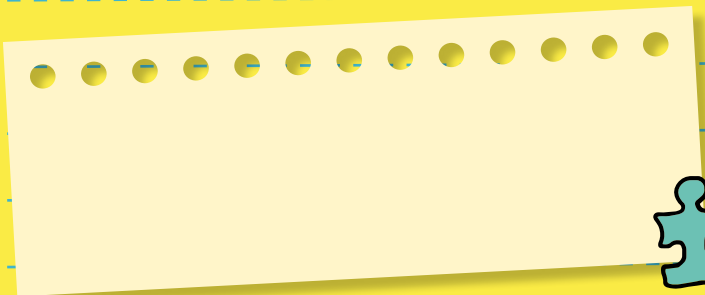
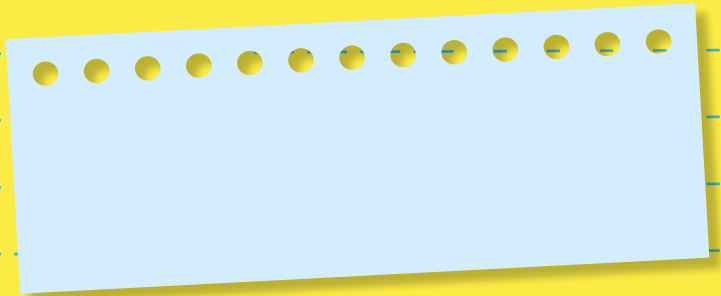
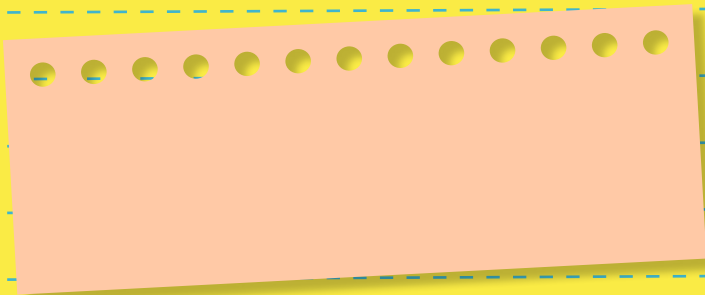
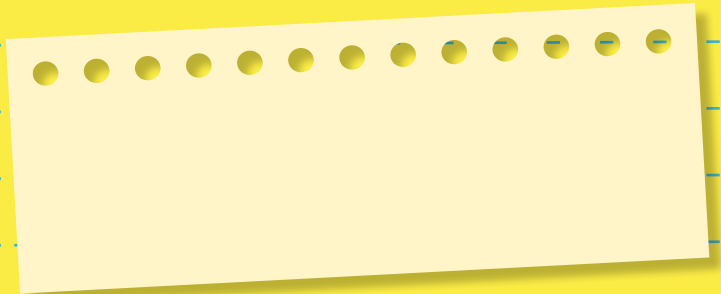
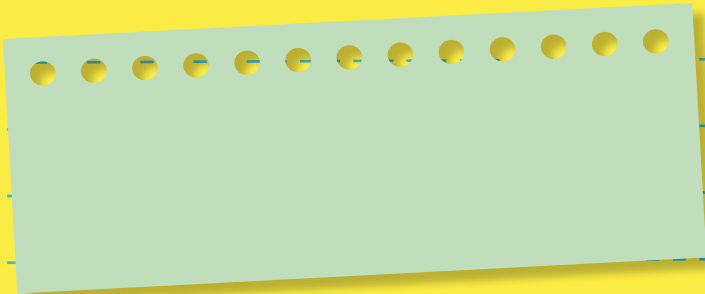
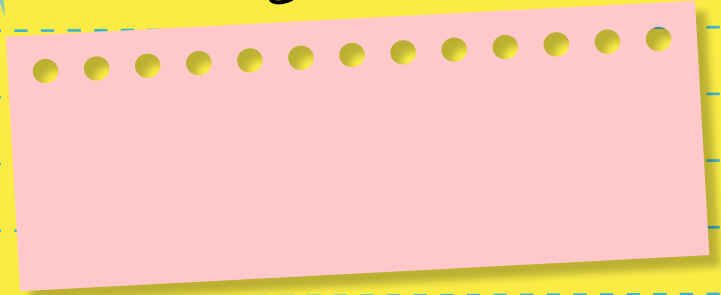
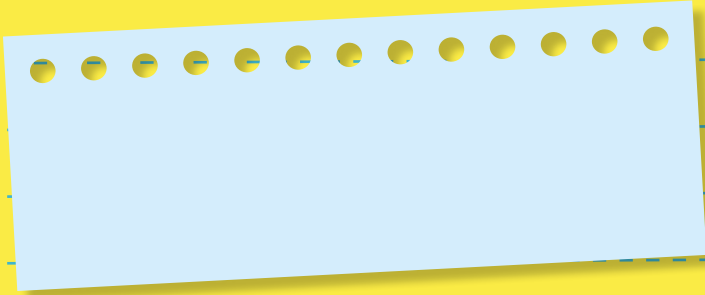
Use this space to make a list of any other essentials that are unique to you - the things you personally need to remember alongside your PN kit.

My notes

Remember to keep your **PN skills tracker** up to date (you'll find it in this book). It's a handy way to track what you've learned, and what you still need to practise.



Questions I have...



Glossary

CVC

A CVC, or Central Venous Catheter, is a special type of tube that goes into a large vein to give medicines, nutrients, or fluids directly into the bloodstream. There are different types of CVCs, such as PICCs, PORTs, and other central lines.

Enteropathy

Refers to any pathology of the intestines

Fistula

An abdominal connection between two body parts such as between the skin and the intestines, causing complications and increased risk of infection.

GDPR

General Data Protection Regulation

HPN

Home Parenteral Nutrition

HPS

Home Parenteral Support

MVA

Microvillous Atrophy. MVA is a condition that some people are born with. It affects the small intestine, which is the part of the digestive system that absorbs nutrients and fluids from food. Because of this, the body can't take in nutrients and fluids in the normal way.

PICC

A Peripherally Inserted Central Catheter (PICC) is a thin tube inserted into a vein in the upper arm. The tip of the catheter sits near the atrium of the heart, like all central venous catheters.

PN

Parenteral Nutrition

TPN

Total Parenteral Nutrition

Your journey, your pace

There will probably be some changes over the next few years: new routines, a new nursing or hospital team, and new responsibilities.

Try not to worry about what's ahead. Any changes will take place gradually and you'll get plenty of support along the way. Over time, you'll start feeling more confident about managing PN yourself.

Keep coming back to this book, ask for help when you need it, and remember – you've got a whole team behind you!

It's what **we** know.

www.lloydsclinical.com

Lloyds
Clinical