NZNIFRS
National Intestinal Failure & Rehabilitation Service

Preparing to take your child home on Intravenous Nutrition (IVN)

“A guide for whānau”

Name:

What is Intravenous Nutrition (IVN)

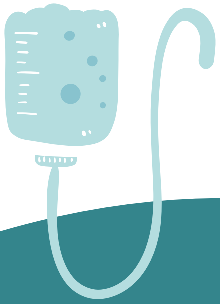
Intravenous nutrition (IVN) helps your child recover, supports gut adaptation, and promotes normal growth and development. It is used when the gut has difficulty absorbing nutrients or when its structure is abnormal.

The gut has an amazing ability to adapt and improve nutrient absorption over time. Our goal is to help your child gradually come off IVN or, if that's not possible, reduce IVN to the minimum needed for healthy growth.
To meet your child's energy needs, they will receive a mix of nutrition through the gut (enteral) and IVN. When your child is unwell, they may need more calories to support weight gain and growth.

IVN is tailored to your child by a dietitian and doctor. It contains proteins, sugars (dextrose), and fats (lipids), as well as electrolytes, minerals, and vitamins. Regular blood tests help adjust the prescription to keep it balanced.

Infection Risks
Infection is the most common risk with IVN. IVN contains sugars and proteins, which can create a good environment for bacteria to grow. Every effort is made to prevent contamination during manufacturing.

To minimise the risk of central line infections, all IVN and central line care is done using strict Aseptic Non-Touch Technique (ANTT) to keep the process as clean as possible.



Going home on IVN

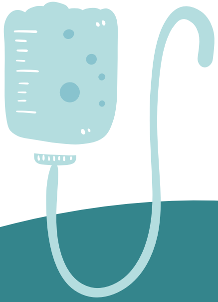
Your child has been diagnosed with intestinal failure and needs intravenous nutrition (IVN) to grow and stay healthy. This is given through a central line. Only a small number of children in New Zealand need IVN at home.

Your care team, including doctors, dietitians, and nurses, will create a plan just for your child. This plan will help manage symptoms and support your child's health goals. Your child will also have an intestinal rehabilitation plan that can be adjusted as needed at home, with a focus on safe and effective care.

We know taking your child home on IVN can feel scary and overwhelming. Caring for a child who relies on medical equipment can be hard work. Before you go home, we'll teach you what you need to know and make sure you feel confident looking after your child.

As your child grows, your family's needs may change. It's important to review these needs regularly. Let us know if your situation changes so we can support you.

This booklet will help guide you as you prepare to go home.
Once you're home, the nurse specialist team and homecare nurses will be your main support. Remember, we're here to help. You can contact your homecare nurse, Nurse Specialist, or the Emergency Department at any time.



Before going home

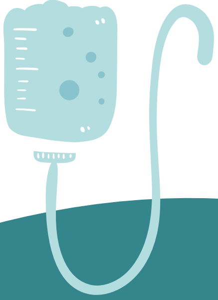
Before discharge the care team will work with you to develop a symptom management plan: This will help the whānau and care team to

- Recognise your child’s normal when well (assessing and understanding your child’s trends is a central focus of care)
- Recognise when your child is having increased symptoms that need early action and close monitoring
- Know what whānau can do - whānau have an action plan and know when to contact the care team for advice

Some care teams use shared care portals so that the care team, whānau and other community health providers can work together following one plan

How do we know it’s safe for your child to go home on IVN?
Clinical stability has been achieved if:

- Blood biochemestry and blood glucose levels are normal
- IVN prescription is stable (IVN can be prescribed for at least 7 days at a time
- Stable daily fluid balance (fluid losses are close to or equal to fluid intake or there is an effective plan in place to manage this which will work at home).
- Vital signs are normal (temperature, pulse, respiration and blood pressure
- Pain if present is well controlled and whānau know how to manage pain relief
- Growth is maintained (your child’s plan will include a goal for weekly or monthly weight gain) - this goal is age dependent



What you can expect from the care team

On initial discharge home you can expect monthly review by the team prescribing your IVN, this may be face to face in clinic or via Microsoft teams or Zoom. A minimum of every second visit should be face to face as physical examination is a really important aspect of health assessment for children and young people with intestinal failure.

Your care team will usually involve: A Paediatrician, Dietitian, Pharmacist, and Nurse Specialist.

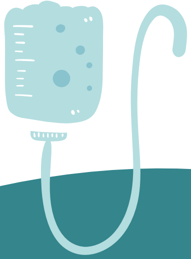
Your first point of contact for health advice will be your community nursing team, who will visit you at home and help with clinical cares such as central line dressings, coordinating health assessment and coordinating monthly blood tests.   You will get to know your community nursing team really well.

If you or your community nursing team are concerned, they will make contact with the hospital based team leading care.

You will also be provided with a plan on who to contact out of hours, and/or when to present to the Emergency department ; you will also be provided with contact details for the ward or specialist nurse coordinating your child’s care

Where do the NIFRS * team fit?
Auckland patients are seen regularly in the Intestinal Failure clinic at Starship. For patients outside Auckland, the NIFRS team work collaboratively with your local paediatric service to provide joint care and telehealth services.

Working together: The whānau and care team will work together to monitor your child’s health; the goal is to detect problems early to avoid further complications



*NIFRS - National Intestinal Failure & Rehabilitation Service

Access to advice

We're here to support you to feel confident and safe managing your child's treatment at home

Your care team

Your first point of contact during business hours Monday - Friday 8am - 4pm is :

Community nursing ____________________

For advice or semi-urgent and planned in-home assessments, the community team manages your care

After business hours, weekends or public holidays contact:

Local hospital __________ the following teams will be able to assist

Local emergency department extension:

Childrens' ward extension:

For issues with IVN supply, deliveries or the infusion pump, please contact your IVN provider. New Zealand has two IVN providers; Baxter Healthcare and Biomed Ltd

Your product specialist will provide the team's contact details and advise when to make contact

In an emergency please dial 111, the call taker will ask standard questions to assess the situation. Explain what has happened and let them know your child is on home intravenous nutrition and has a central line

Emergency management plan

Before you go home we will teach you how to recognise signs that your child's condition is worsening, when to be concerned, and what actions to take. You will also receive a personalised symptom management plan with steps to follow and guidance on when your child needs urgent medical review

My child's normal is:

People living with intestinal failure and relying on intravenous nutrition may face three main challenges: **central line infections, mechanical problems with the central line, and dehydration** due to changes in gut function

Your child's emergency plan will depend on how far you live from your local hospital

If your child has a fever, we need to check for infection. Please avoid giving Paracetamol until we decide if blood cultures are needed.

Seek advice and help immediately:

If you notice that your child has the following:

- Difficulty breathing - call 1 1 1 - Ambulance staff will ask you standard assessment questions, it is always ok to ring them back to provide an update if things change.
- Signs of low blood sugars
  - dizziness, fatigue, sweating, tremors, pale skin, confusion and a significant change in behaviour and increased irritability. (If your child is due to start their IVN infusion, commence the infusion)
- High temperature - including shakes and chills
  - Two temperature readings of 38.0 measured within 30 minutes
  - One temperature of 38.5 +
- Unexplained vomitting
- Jaundice (child's skin or whites of their eyes turn yellow)

Issues with your child's central venous access device (CVAD)

- Ballooning, bulging , a split or hole, leaking around the exit site or from the line. (If these are present the line is not safe to use and requires a nursing assessment and plan for possible repair)
- Bleeding from the exit site
- Redness, pain, pus or ooze from the exit site - this may signal and exit site infection which will require treatment
- Skin pulling away from the CVAD exit site
- Swelling of your child's hand, arm, back or torso - this will signal that the CVAD may have moved within the blood vessels and that the CVAD is not safe to use
- A blocked CVAD - do not attempt to unblock the line at home through applying pressure, this may cause the line to break - under most circumstances we can rescue a blocked line.

If you notice that the CVAD has moved (the external length appears longer or shorter) secure the line with tape and notify the Nurse Specialsit or ward immediately - please don't push the CVAD back into the vein this will cause an infection

CVAD details

Type of CVAD (PICC, tunneled line or Portacath)

Date inserted

Name of surgeon

Size (french)

Site inserted (which central vein):

External length :

Port needle size :

CVAD management plan

Type of dressing

Skin cleaning solution

Line Lock frequency and volume:

Additional information: **(It is helpful to record the number of lines your child has had and any allergies to dressings or cleaning solutions)**

Day to day living

Your child can shower or bath, but the CVAD dressing only protects against water spray

- Cover the CVAD site with a plastic bag or plastic wrap (press and seal or similar) during bathing or showering to keep the dressing dry
- If the dressing gets wet, contact your home care nurse for a dressing change

Clothing

- Infants: Use one-piece outfits to prevent accidental pulling on the CVAD
- Older children/teens: loose fitting, long sleeve tops work best to stop them from touching the CVAD
- If your child has a PICC line, we can provide a stretchy ‘TubiGrip sleeve for extra protection

Play activities

- Avoid “rough” or active play that could damage the CVC.
- Your child's line needs to be fully protected when playing outside. Avoid exposure to sand and dirt to keep the line safe.
- If your child wants to join in water-based activities or sports, talk to your doctor or nurse specialist to plan how to do this safely.

School and daycare

We encourage your child to keep attending school or daycare while on IVN

- With planning and communication, your child can continue learning, playing and spending time with friends
- If your child wants to play sports, discuss it with your doctor or nurse specialist first

.

My child’s daily routine

Document your child’s routine here

My child receives IVN Hours per day

IVN connection time O’clock

IVN disconnection time O’clock

CVAD weekly dressing change happen on (Day of week)

CVAD site checked minimum 3 - 4 x daily

Medication times

Oral diet

☐ YES

☐ NO

Enteral feed (continuous)

Hours per day

Time off feed

Enteral feed

Bolus times

Bolus volume

My child’s daily routine

Consider skin cares, mouth cares, developmental needs, nap times

Morning routine

Afternoon routine

Evening routine

Note: Your child will likely pass the majority of their daily urine volume overnight, as this is when they receive the majority of their daily fluid requirement

Goes to sleep

Understanding intestinal rehabilitation

How the gut heals

The gut continues to adapt and improve after an injury, but this is a slow process that can take years. Over time, nutrient absorption may improve, allowing for a gradual reduction in IV nutrition (IVN) and an increase in enteral (tube or oral) feeding.

Why we adjust IVN

Changes to IVN prescriptions are made to:

- Support growth and development
- Reduce risks (e.g., liver issues, infections)
- Encourage the gut to work more effectively

Symptom management

- Blood Sugar Control – IV nutrition can affect blood sugar levels, so we monitor and adjust as needed.
- Fluid Balance – IV fluids may be adjusted to prevent dehydration or fluid overload.

Monitoring and records

Ongoing monitoring helps keep IVN safe and effective. This includes:

- Regular blood and urine tests to check nutrition and hydration (this will occur monthly when your child is first discharged, and minimum 3 monthly)
- Keeping records of weight, fluid intake, and symptoms

Reducing IVN and increasing feeds

The goal is to increase enteral feeds when the gut can absorb more. This transition happens gradually based on:

- Nutrient absorption and tolerance
- Growth and hydration status

Every child’s circumstances are unique, and the care team will adjust treatment to support their best possible nutrition and development.

What is a Central Venous Access Device

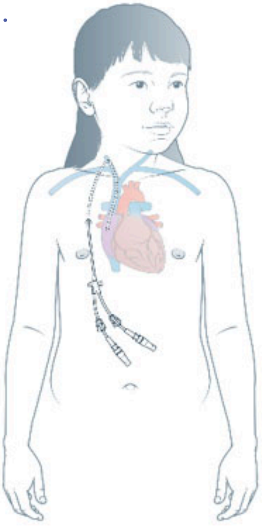
A CVAD is a thin tube that provides direct access to large blood vessels through an external access point. It is used for:

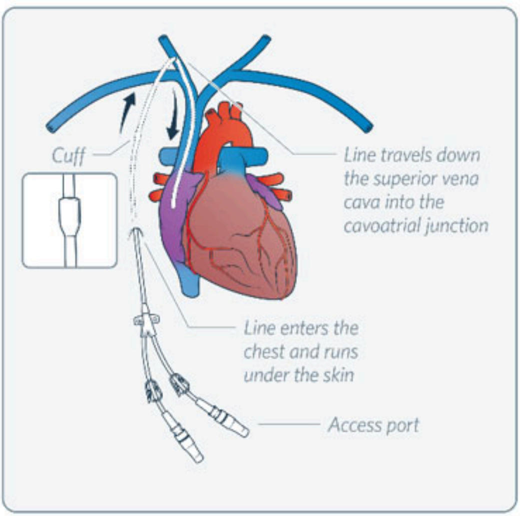
- Delivering medications that cannot be given by mouth
- Administering intravenous nutrition (IVN) when a child cannot grow or develop properly with oral intake alone
- Taking frequent blood samples to reduce the discomfort of repeated blood tests

Central Line Placement

There are six major blood vessels where a central line can be placed. Whenever possible, we use upper body vessels for IVN.

In some cases, lower body vessels like the femoral vein or inferior vena cava may be used if upper body veins are not suitable. Upper body placement is preferred as it often provides better function and reduces complications.





Key parts of the CVAD

Key parts of the central venous access device (CVAD) are the parts that must stay clean to prevent infection. These include:

- Needles
- Syringe tips
- Needleless connections
- Exposed central line lumens

Keeping these parts sterile is essential to reduce the risk of infection.

If your child is receiving IVN, we will use a single-lumen line whenever possible to lower the risk of infection

image sourced from: Kids Health Info :
CVAD: Tunnelled Cuffed - Centrally Inserted Central Catheter TC-CICC (rch.org.au)

Types of CVAD

Tunneled Catheter

A tunneled catheter is placed under the skin and anchored by a small cuff beneath the skin.

- It can be used for several months to years.
- In growing children, the line position may need regular X-ray checks.
- **Important**: If the cuff becomes visible under the dressing, contact the nurse specialist team immediately. This increases the risk of infection and accidental removal.

PICC (Peripherally Inserted Central Catheter)

A PICC is placed in your child’s arm and secured with a device called a 'SecurAcath.' This device sits just under the skin in the subcutaneous layer to help keep the line firmly in place.

Port-a-Cath (SCVAD)

A port-a-cath is a small device surgically implanted under the skin, consisting of two parts:

1. **Port:** A small chamber placed under the skin of the chest, arm, or abdomen.
2. **Catheter:** A tube attached to the port that connects to a large vein near the heart.

- When needed, a special needle is used to access the port through the skin.
- Once healed, the port feels like a small lump under the skin.

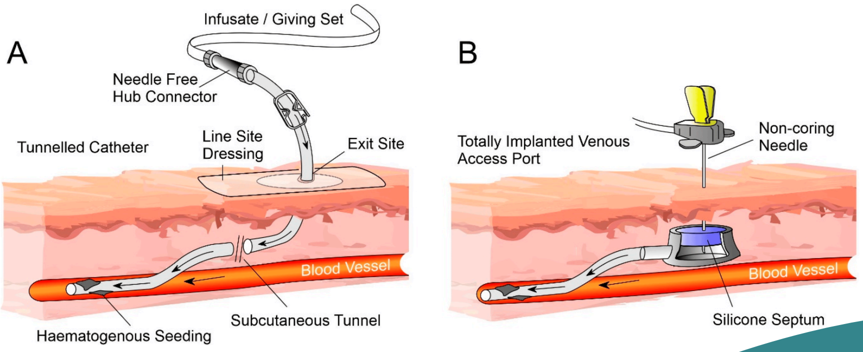


image sourced from: Medicines 2020, 7(9), 49;
https://doi.org/10.3390/medicines7090049
(Minimising Blood stream infection

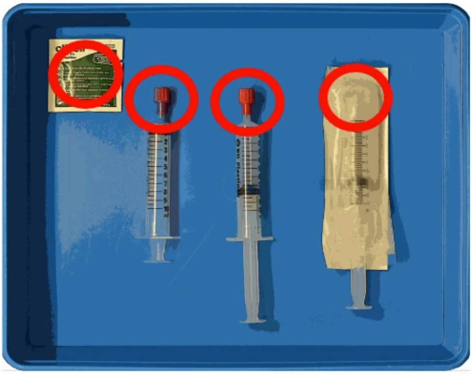
What is Aseptic Non-touch Technique (ANTT)

Aseptic Non-Touch Technique (ANTT) is a method used to keep medical procedures as clean as possible to reduce the risk of infection. It focuses on protecting the parts of medical equipment, like needles and central lines, that must stay sterile.

Key principles of ANTT include:

- Hand hygiene: Cleaning hands thoroughly before starting any procedure.
- Non-touch technique: Avoiding direct contact with key parts, such as syringe tips or catheter hubs, to prevent contamination.
- Sterile equipment: Using clean and sterile items for every procedure.
- Clean environment: Ensuring the work area is tidy and free of unnecessary items that could introduce germs.

By following ANTT, we help ensure that your child's care is safe and reduces the risk of complications.



You will be taught standard ANTT (without gloves) as part of learning how to care for your child’s IVN. This technique helps minimise mistakes, especially when it comes to handling gloves and keeping everything sterile.

Hand hygiene

Hand washing is the single most effective measure to prevent infection when completing line cares

5 ways to prevent line infections

1. **Wash your hands** before, during and after IVN-related cares
2. **Monitor the exit site dressing** to ensure it stays intact at all times
3. **Apply ANTT principles** (Aspetic Non-Touch Technique to keep the line clean
4. **Lock the CVAD** when it’s not in use (more details to follow)
5. **Use a chlorhexidine cap** on the end of the needleless connector (access port) when it’s not in use

Also: minimise the number of times you access the line

Your child will have single lumen CVAD, this also greatly reduces the rates of infection

Locking the CVAD

- The NIFRS team recommend the use of line locks to prevent catheter related bloodstream infections
- Your child should be commenced on a daily line lock when it has been identified that they will require medium to long term IVN
- For neonates a line lock is commenced when the line is not continuously in use 24 hours a day
- Your medical team will identify the best product for your child
- KiteLock or Taurolidine are both suitable locks. Most paediatric patients are on KiteLock

KiteLock

- **Prevents infection** by eliminating biofilm in the line - reducing the ability for bacteria and fungi to grow within the line
- **Acts quickly**, begins working within 30 minutes of administration
- **Reduces blockages -** helps prevent clots keeping the line open and functional and prevents the development of a fibrin sheath
- **Safe for flushing** if the CVAD cannot draw back blood, KiteLock can be safely flushed through the line

KiteLock is administered at IVN disconnection and remains in the line until the next line access

- **Tunelled CVAD** - **Under 1yr** receives 0.5ml; **Over 1yr** - 1 - 2ml (can remain insitu for up to 1 week)
- **Portacath** 2ml (can remain insitu for up to 1 month)

Signs of blockage:

- Increased pressure when you flush the line
- Unable to flush the line
- Ballooning of the line when flushing

Prevention of blocks

- Always flush the line using a push/pause technique
- Always flush the line if blood can be seen in the line
- Always flush the line when the IVN infusion is finished

Securing the CVAD

To prevent accidental removal

always

Loop the line under the dressing

To prevent line breaks

Always ensure that:

- the catheter joint sits under the dressing
- the clamp is placed on the thicker part of the line

CVAD dressings are renewed weekly or if the dressing has lifted
The exit site and surrounding skin requires assessment when completing normal cares such as

- ☐ Bathing
- ☐ Nappy changes
- ☐ IVN disconnection
- ☐ IVN connection
- ☐ Increased irritability or scratching

The team will also talk to you about distraction techniques that you can use when completing CVAD cares

Monitor the exit site for:

- Redness
- Swelling
- Pain or tenderness
- Discharge or oozing
- Dressing lifting or becoming wet

Monitor the line for changes in pressure when flushing and any ballooning

Please discuss with your CNS if you observe any of the above

Setting up your home

The home IVN provider organises:

- Delivery of Intravenous Nutrition to home (you will be provided with a delivery schedule)
- an Infusion pump, pump clamp, IV pole and backpack
- ongoing supply of administration sets
- A tray for set-up (IVN connection and disconnection)
- A fridge for storage of IVN and medications (food cannot be stored in this fridge)

Community nursing provides:

- All other consumables to support management at home
    - Posiflush syringes (6 per day)
    - 2% chlorhexidine /alcohol prep-pads (10 -12 per day)
    - Chlorhexidine caps to protect CVAD access port
    - 10 ml syringes (1 per day for KiteLock)
    - 23g needles (to draw up daily KiteLock)
    - Enteral syringes for oral medications and feeds
    - Enteral feeding supplies and a spare feeding tube
    - Wipes for cleaning surfaces and gloves
    - Stoma supplies (if applicable)
- You will often receive a month’s supply of consumables at once. It’s important to track your usage and understand which items are single-use and which can be reused.
    - **Single-use consumables** - Items used to connect or disconnect IVN or administer IV medications
    - **Multi-use consumables** - Items for delivering medications or feeds via an enteral feeding tube (these must be sterilised or cleaned between uses).
- If you have concerns about supplies please talk to your community nurse

The **Hospital dietitian** will arrange an enteral feeding pump for you to take home

Preparing for the transition home:
Key questions to plan and get organised

Storage and supplies

- How much space do we have for storing equipment and supplies?
- What can I do to make the best use of the space we have
- Do we already have personal supports or resources to help with this?
- What would make organising supplies easier for our whānau

Planning for IVN connection and disconnection

- Can someone help by watching my other children or supporting me during IVN connection and disconnection times?
- How can I set up a regular routine or “protected time” for these tasks?

Setting up IVN at home

- Where will I set up the IVN at home?
- Is there a sink or location nearby where I can wash my hands properly?
- How will I safely dispose of rubbish after each IVN sessioin?

Managing IVN deliveries

Before going home your delivery schedule will be confirmed by the team.

- Will someone be home to receive IVN deliveries?
- If not do we need a cool box or another solution to safely store IVN supplies until we return home?

These questions can help guide your planning and identify any areas where you might need additional support

IVN connection

Getting ready

- Remove the IVN from the fridge **2 - 4 hours** before connection. (IVN needs to be close to room temperature for mixing and patient comfort)
- Keep the pump fully charged by putting it on charge after each IVN disconnection. Also check that the 9V battery is full to ensure it's ready for the next connection

Hand hygiene (key moments)

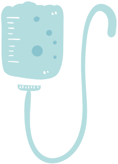
Hand wash (20 - 30 seconds- dry hands completely after)

- At the start of the process (before cleaning surfaces)
- Before spiking the IVN bag
- Before accessing your child's line
- After completing the IVN connection

Hand sanitizer can be used as needed throughout the process

These steps may feel repetitive, but are vital to preventing line infections and ensuring your child's safety

Supply gathering



- IVN bag (with prescription available for checking)
- Administration set
- Posiflush syringes (pre-filled saline) 3 - 4
- 2% chlorhexidine /alcohol prep-pads 8
- Tray (for clean field); IV pole or backpack
- Tape
- Small rubbish bin or similar
- Clean hand towel (changed daily)

Assessment before connection:

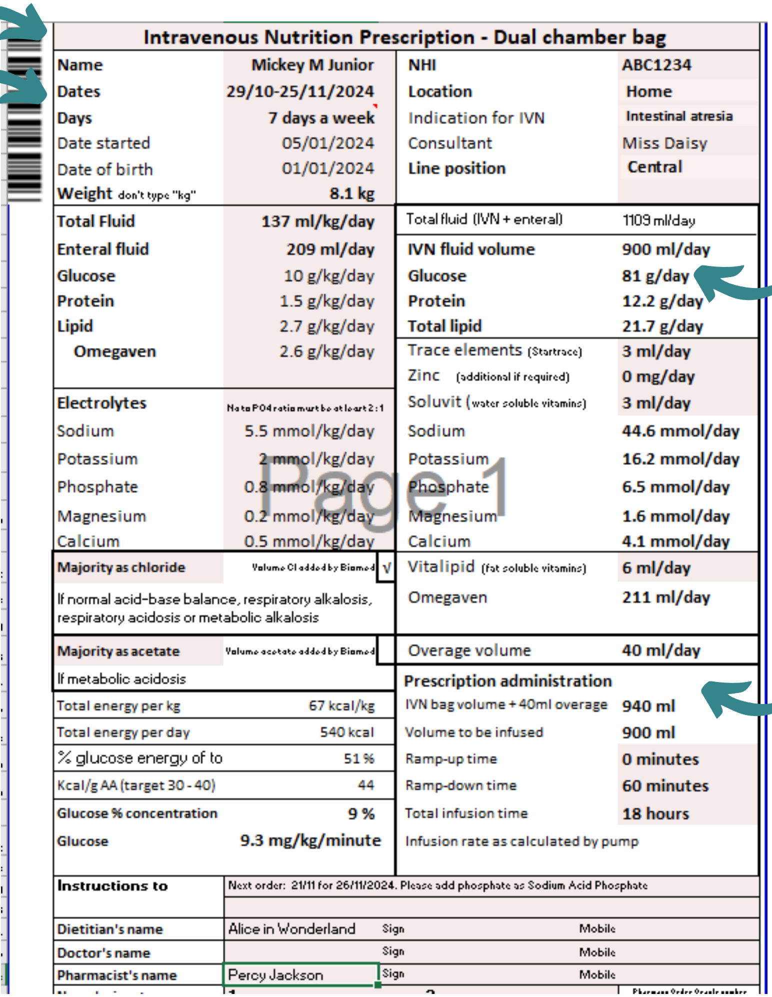
- **CVAD checks**
  - Ensure the dressing is intact and doesn't need reinforcement or changing
  - Confirm catheter has no obvious splits or breaks
- **Child's condition** Take temperature and assess for signs of infection or illness

Checking the IVN prescription

always Check the prescription against label on the actual IVN bag - remove the IVN from inside the black bag

Check

- Your child's name and date of birth are recorded correctly
- Prescription dates match the bag expiry dates



Intravenous Nutrition Prescription - Dual chamber bag

Name	**Mickey M Junior**	**NHI**	**ABC1234**
Dates	**29/10-25/11/2024**	**Location**	**Home**
Days	**7 days a week**	Indication for IVN	**Intestinal atresia**
Date started	05/01/2024	Consultant	Miss Daisy
Date of birth	01/01/2024	**Line position**	**Central**
Weight don't type "kg"	**8.1 kg**		
Total Fluid	**137 ml/kg/day**	Total fluid (IVN + enteral)	1109 ml/day
Enteral fluid	**209 ml/day**	**IVN fluid volume**	**900 ml/day**
Glucose	10 g/kg/day	**Glucose**	**81 g/day**
Protein	1.5 g/kg/day	**Protein**	**12.2 g/day**
Lipid	2.7 g/kg/day	**Total lipid**	**21.7 g/day**
Omegaven	2.6 g/kg/day	Trace elements (Startrace)	**3 ml/day**
		Zinc (additional if required)	**0 mg/day**
Electrolytes	Na to PO4 ratio must be at least 2:1	Soluvit (water soluble vitamins)	**3 ml/day**
Sodium	5.5 mmol/kg/day	Sodium	**44.6 mmol/day**
Potassium	2 mmol/kg/day	Potassium	**16.2 mmol/day**
Phosphate	0.8 mmol/kg/day	Phosphate	**6.5 mmol/day**
Magnesium	0.2 mmol/kg/day	Magnesium	**1.6 mmol/day**
Calcium	0.5 mmol/kg/day	Calcium	**4.1 mmol/day**
Majority as chloride	Volume Cl added by Biomed √	Vitalipid (fat soluble vitamins)	**6 ml/day**
If normal acid-base balance, respiratory alkalosis, respiratory acidosis or metabolic alkalosis		Omegaven	**211 ml/day**
Majority as acetate	Volume acetate added by Biomed	Overage volume	**40 ml/day**
If metabolic acidosis		**Prescription administration**	
Total energy per kg	67 kcal/kg	IVN bag volume + 40ml overage	**940 ml**
Total energy per day	540 kcal	Volume to be infused	**900 ml**
% glucose energy of to	51 %	Ramp-up time	**0 minutes**
Kcal/g AA (target 30 - 40)	44	Ramp-down time	**60 minutes**
Glucose % concentration	**9 %**	Total infusion time	**18 hours**
Glucose	**9.3 mg/kg/minute**	Infusion rate as calculated by pump	
Instructions to	Next order: 21/11 for 26/11/2024. Please add phosphate as Sodium Acid Phosphate		
Dietitian's name	Alice in Wonderland	Sign	Mobile
Doctor's name		Sign	Mobile
Pharmacist's name	Percy Jackson	Sign	Mobile

Ensure that:
The ingredients match

Find the details here for programming the infusion pump

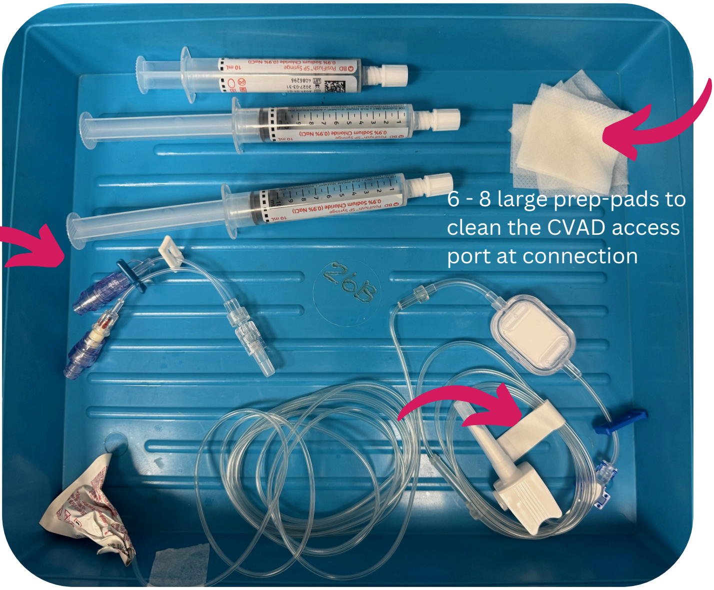
Keep the IVN bag in the black bag to protect it from light, as prolonged exposure can reduce the effectiveness of some nutrients

Preparing your tray

Your tray acts as the clean field. Wipe down the tray and nearby surfaces with antibacterial wipes before opening and placing supplies in it.

2 - 3 10ml posiflush syringes (contains normal saline)

- Syringe 1 - discard 8ml leaving 2ml for to check the CVAD is working
- Syringe 2 - 10mls to flush the line at connection
- Syringe 3 - 10ml syringe for priming Y connector if needed at home



6 - 8 large prep-pads to clean the CVAD access port at connection

As an inpatient we use **Y-connectors,** you will be taught how to prime and connect the Y-connector in case this is needed at home

1 administration set

- Check the expiry date (printed on the packaging)
- Open onto the tray without touching the key parts
- Close the blue clamp
- Remove the paper tapes
- Place the end of the administration set (with green cap) into a Prep pad packet and tape to the tray to protect against any accidental contamination

When preparing the syringes

- Loosen the white cap, draw back on the syringe to break the seal (the syringes are airlocked for protection)
- Prime the syringe, removing air bubbles

Activating dual chamber IVN bag

1 Remove the IVN from both the black and clear plastic bags (keep the black bag aside)

2 Complete the IVN bag checks

Ensure the lipid chamber looks evenly mixed and consistent

Check the aqueous chamber appears clear

3

Lay the bag on a flat surface,
Turn the bag over so the green pull tab is facing the table

4

Pull the white tube towards you while holding the bag steady with your other hand.

Alternatively, hold the green pull tab (like the spine of a book) to steady the IVN bag, then pull the white tube towards you to remove it.

5

Fold the lipid chamber over and remove the green pull tab

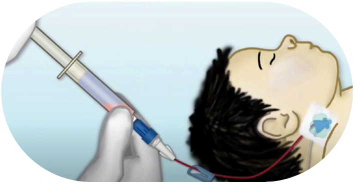
6

Gently place pressure on either side of the bag to mix the bag

✓ READY TO USE

Connecting IVN to the CVAD

REMEMBER



1. Complete hand hygiene and CVAD checks before proceeding

2. Clean the needleless connector for 30 seconds - this has been shown to reduce the rate of central line infections - allow the line to dry for up to 30 seconds

3. Remove the white cap from the syringe containing 2mls of normal saline, be careful not to touch the catheter tip

4. Connect the syringe to the Central line; it is important that a second carer is either distracting your child while you do this, or gently holding their hands to avoid accidental contamination of the syringe or CVAD

   Check for blood return - by drawing back on the syringe (2ml draw back is required to ensure patency and removal of any line lock which may be sitting in the line)

5. Clean the needleless connector for 10 seconds, allow to dry

   Attach the second syringe (10ml normal saline)

   Flush the line using a push pause turbulent flow technique

   Do not proceed with IVN connection if you note: fluid leaking at the exit site; discharge from the exit site; or any ballooning or leaking from the central line when flushing.

   Also observe and monitor the pressure in the line when flushing if this changes it will be important to arrange for the care team to review the line

   Be careful to not flush the line to quickly, this can be very uncomfortable and cause a variety of side effects - such as headache and nausea

6. Repeat - 10 second CVAD clean and proceed with connecting IVN

IVN disconnection

IVN disconnection should occur as soon as possible after the IVN has finished.

Equipment

2x 10ml posiflush syringes (contains normal saline)

- Syringe 1 - discard 8ml leaving 2ml for to check the CVAD is working
- Syringe 2 - 10mls to flush the line at disconnection
- Needle and a 10ml syringe to draw up CVAD lock 0.5 - 2mls depending on age and device type

- Prep the syringes and line lock using ANTT ensuring that the key parts are not contaminated

Practice points - Hand hygiene is key

- When preparing the syringes loosen the white cap, draw back on the syringe to break the seal (the syringes are airlocked for protection)
- Prime the syringe, removing air bubbles
- Your pump will continue to deliver a small amount of IVN while you get ready, this makes sure that the line doesn't become blocked
- The line lock remains insitu until the next time the CVAD is required

REMEMBER

Always ensure that:

- the catheter joint sits under the dressing
- the clamp is placed on the thicker part of the line

Responding to fever

Normal body temperature for children under one year is up to 37.5 degrees celcius

Over 1 year is up to 37 degrees celcius

- High temperature - including shakes and chills
    - Two temperature readings of 38.0 measured within 30 minutes
    - One temperature of 38.5 +

If you live close to your local hospital - we would recommend that you present to your local emergency department for assessment immediately

If you live some distance from the hospital and may need to wait for an ambulance to arrive to access assistance; your care team may teach you to collect a blood culture from the CVAD

This will be done as part of your training

Do not give Paracetamol to your child before they have been assessed, if your child has a line infection it is important that the type of bug can be identified as soon as possible so that antibiotics can be targeted to for that bug - we can only identify bugs in blood when the temperature is high

Please monitor the expiry dates on the blood culture bottles they have short expiry dates and need to be replaced regularly - they are not reliable if they have expired.

Community CVAD problem solving:

For any of the following problems, identify the problem, assess and if they persist contact the nursing team or after hours support as per your access plan:

If there is a tear, hole, break or air in the CVAD

- Keep calm, it may be possible to repair the CVAD
- Use the clamp from the CVAD safety pack, clamp the CVAD between the break and child's body
- If a clamp is not available, fold the CVAD back on itself, wrap in sterile gauze and tape it in place. This will work the same as clamping the line.
- Arrange for the line to be reviewed by the hospital based nursing team

Your child has accidentally pulled the CVAD or caught it on something

- Check the exit site for signs of bleeding or trauma
- If bleeding, apply direct pressure to the area of bleeding with sterile gauze
- If the CVAD appears to be displaced, please contact the team and take your child to the emergency department for assessment and a chest x-ray. If the line is displaced and unsafe for use, plans will be made for a replacement line.

If the CVAD is difficult to flush

- Check that there are no kinks in the line
- Apply gentle pressure when flushing the CVAD
- Try drawing back the syringe plunger back and forth gently

If you are **unable to withdraw blood from the CVAD** - movement such as swinging the arm, coughing, bending over, or going for a walk can help; try again and if this doesn't work contact your nursing team

- We recommend that the health team provide whānau with a Gusgear CVAD vest to protect the line - it provides `whānau and the health team with peace of mind

Community CVAD problem solving:

Dressing unsecured?

- Replace the dressing or cover the peeling dressing and contact your community nursing team
- Dressing changes for infants and small children routinely require 2 adults, one to distract the child and keep them calm and the other to apply the dressing under sterile technique

The needless connector has come off - seek advice

- Make sure that the CVAD is clamped, clean the exposed end with an alcohol swab, allow to dry and apply a new needleless connector - you will be taught how to change needleless connectors as part of your practical home IVN training (these are routinely changed 1 - 2 x per week depending on local policy)

The CVAD gets covered in mud or dirt - seek advice

- Clean the CVAD, It may be necessary to change the dressing or needleless connector if they are visibly dirty

The administration set will be considered as unsafe to use under the following circumstances

- IVN bag and administration set dropped
- Key parts of the adminstration set touched during connection
- Administration set becomes disconnected at any time during the infusion
- Administration set or CVAD are soiled with bodily fluids

Action plan

- Stop the IVN infusion
- Assess the key parts of the CVAD for level of contamination
- Replace the needleless connector and dressing as required
- Hang a new bag of IVN if available
- Alternatively hang an emergency bag of fluids depending on available supply
- Contact the care team as per your access to advice plan

Assessing skin

Children living with intestinal failure often have multiple tubes that need to be secured with dressings. Frequent use of dressings, adhesives, and cleaning solutions can irritate the skin, causing redness, dryness, or soreness. Checking your child’s skin regularly and using gentle care can help prevent irritation and keep their skin healthy."

Recognising early signs of skin irritation (contact dermatitis)

- Skin redness, the skin can appear darkened or leathery (dry)
- Extreme itching

Worsening signs to watch for

- Blistering
- Cracking skin: Cracked, extremely dry skin can be very painful and may cause distress, especially during dressing changes

When to seek immediate help

- Weeping skin
- Ulceration, open sores that form crusting

What is hyper-granulation tissue

- Granulation tissue forms as part of the normal healing process.
- Hypergranulation tissue can develop when healing happens too quickly or when there is increased bacteria on the skin.
- It appears as an overgrowth of pink, moist tissue that bleeds easily when touched.
- Hypergranulation commonly occurs around tube sites, such as CVADs and gastrostomies.
- If left untreated, it can increase the risk of infection.

The best approach is to take action as soon as you notice any signs of skin irritation.

Skincare recommendations

Standardised dressing plan

- **Change the dressing:** Every 7 days, or sooner if it gets wet, dirty, or loose
- **Inspect the site:** Check for signs of infection (redness, swelling, or discharge) or irritation
- Clean the skin: Use antiseptic wipes to clean around the site, then let it dry before applying a new dressing
- **Apply a new dressing**: Use a clean, sterile, transparent breathable dressing to cover the site. These dressings allow the skin to breath while keeping the area secure and protected
    - **Note:** Each hospital may use different products, but they all serve the same purpose to protect the site and keep the line secure
- **Check the dressing:** Make sure it stays in place and isn't too loose or wet
- **Comfort:** If the dressing causes discomfort or irritation, talk to the care team for alternatives

The goal is to keep the site clean, dry and secure to prevent infection, while allowing the skin to breath and the line to stay in place

Approach

1. Identify the source of irritation ?
The source of irritation can be caused by either the dressing, the cleaning solution, or both. Chlorhexidine is a common cleaning solution, and many children may develop an allergy to it, which can cause skin irritation or a rash. If irritation occurs, consider switching to a different cleaning solution first. Additionally, a short course of antihistamine may be recommended to help manage the allergic reaction and soothe the skin

2. Try the next available transparent dressing if irritation occurs. Your care team will have several different products they can use, and will choose the best option for your child's skin based on their preferences and experience

3. Trial the Starship Contact Dermatitis protocol to calm the skin, the careteam may decide to complete patch testing to check for allergies and or refer to a specialist skin doctor for advice

Discharge planning checklist

Caregiver Checklist

☐ Whānau identify a primary caregiver
☐ Two caregivers are trained to provide ongoing care at home
☐ Caregivers are involved in health-related decision-making
☐ Caregivers understand the risks and benefits of IVN
☐ Caregivers work with the clinical team on the intestinal rehabilitation plan
☐ Caregivers can be reliably contacted
☐ Caregivers know when to seek advice if they or their child are unwell

Housing Suitability

☐ Home assessment completed to ensure suitability
☐ Access to power ; ☐ Access to heating ; ☐ Access to refrigeration
☐ Hot and cold running water
☐ House is not overcrowded
☐ Contactable by phone

Financial Supports

☐ Financial supports in place (child disability and carer support)
☐ Family has access to respite options
☐ Social supports identified

Emergency Management Plan

☐ CNS (Clinical Nurse Specialist) develops an emergency management plan for possible infection and dehydration with medical and dietetic staff

Emotional Safety

☐ Caregiver and whānau encouraged to engage with psychology assessment and support

Care Team

☐ Care team identifies appropriate referrals
☐ Discharge planning meetings and actions agreed
☐ Personalised care plan developed with whānau

Staged Discharge

☐ Auckland patients may have a staged transition home depending on geography and child’s stability

Discharge

☐ **Estimated date of discharge: _________**

Whānau questions / notes

Whānau questions / notes

NZNIFRS
National Intestinal Failure & Rehabilitation Service

NIFRS clinical guidance can be located via the Starship clinical guidelines