



# THE GENTLE NICU SURVIVAL KIT

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# ADVOCATE FOR YOURSELF

in healthcare settings



## 3 Key Questions to ask BEFORE agreeing to any medical procedure:

1. **What are my options** and what does each of them involve?
2. **What signs/symptoms** am I showing that have led you to this decision?
3. **What do you expect to happen** if I choose to wait or if I take no action?

## KEY THINGS TO LOOK OUT FOR



### Green Flags

- ✓ The Doctor explains Pros and Cons clearly
- ✓ You are given a choice between paths
- ✓ Your concerns are listened to & questions answered clearly
- ✓ You feel confident in understanding your choices



### Red Flags

- ✗ You are pressured to sign or decide immediately
- ✗ Questions dismissed or answered vaguely
- ✗ You are discouraged from getting a second opinion
- ✗ Told “standard procedure” without explanation for your case

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# NICU Terminology

& what it means for you



*Breathing*

Terminology	What it means	Goal	Advocacy
<b>Intubate Extubate</b>	A breathing tube placed through the mouth/nose into the windpipe, connected to a ventilator.	Removing the tube (extubate) and moving on to Non-invasive ventilation (NIV)	Ask about "Sedation" or comfort meds. An intubated baby should look comfortable, not fighting the tube.
<b>CPAP BiPAP</b>	Constant air pressure to keep lungs open. BiPAP adds a "timed" extra puff.	Lowering the "pressure" number (e.g., from 8 to 5).	Check for "CPAP Belly" (bloating). Ask for a "mask break" to protect the skin on the nose.
<b>High Flow / Low Flow</b>	Warm air through nose prongs. High Flow has "pressure"; Low Flow is just extra O <sub>2</sub> .	Moving from Liters (Flow) to "Room Air" (0.21 or 21%).	Watch for "retractions" (skin pulling in around ribs). This means they are working too hard.
<b>FiO<sub>2</sub></b>	The percentage of oxygen in the air mix. Room air is 21%.	Getting as close to 21% as possible.	If the number jumps up only when baby is crying or pooping, don't panic—it's a temporary "dip."
<b>Blood Gas</b>	A tiny blood poke to check CO <sub>2</sub> and pH levels.	pH should be 7.35-7.45. pCO <sub>2</sub> shows if they are "tiring out."	If the "Gas" is bad but the baby looks great, ask if the sample was "capillary" (heel poke), which can sometimes be less accurate.
<b>Desat / Brady</b>	Desat: Oxygen drop. Brady: Heart rate drop.	"Self-recovering" (fixing it without help).	Keep a log of when these happen. If they only happen during feeds, it might be reflux, not a lung issue.

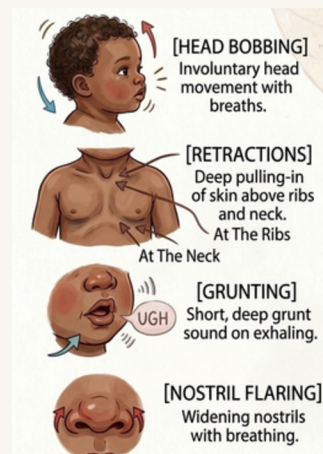
**What to Watch for:**  
signs your baby is working hard to breathe

Head Bobbing

Retractions

Grunting

Nostril flaring





Feeding

# NICU Terminology

## & what it means for you



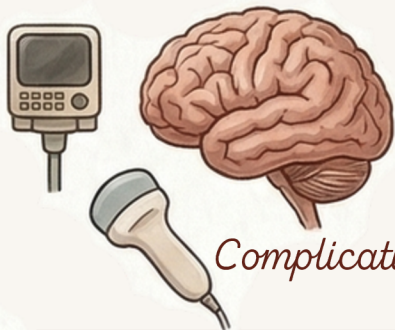
Terminology	What it means	Goal	Advocacy
<b>NG / NJ Tube</b>	NG: To stomach. NJ: Past stomach into the small intestine.	Moving from "Continuous" (all day) to "Bolus" (every 3 hours).	Use a dummy/pacifier during tube feeds. It helps the baby associate the feeling of a full tummy with sucking.
<b>Gravity Feed</b>	Letting milk flow in by height/gravity rather than a pump.	Feeding at the baby's own pace, like a real bottle.	Observe the speed. If it goes in too fast, the syringe can be lowered to slow the flow down.
<b>TPN (IV Food)</b>	A liquid mix of protein, fats, and sugar sent directly into the blood.	Seeing the "Milk Volume" go up while the TPN bag gets smaller.	TPN can be hard on the liver. Ask: "Are we tracking 'Direct Bilirubin' to check liver health?"
<b>Stomach pH</b>	A test to check if the feeding tube is in the right spot (acidic stomach vs. lungs).	A pH level of 5.5 or lower (this confirms the tube is in the stomach).	If the baby is on antacids (Pepcid), the pH will naturally be higher. Don't let it stall a feed unnecessarily.
<b>Aspirate (Residuals)</b>	Milk or formula left in the stomach from the last feed.	Finding little to no milk (meaning the baby digested it all).	If it's Bright Green (Bile), tell the nurse immediately. This is a "Stop" sign for feeding.
<b>Reflux (GER)</b>	When milk and stomach acid travel back up the "food pipe."	Fewer "spit-ups" and less arching or discomfort after meals.	Ask about "Pacing." Slower feeds or smaller, more frequent meals often fix reflux better than meds.

### Bonus Tip:

Ask your nurse if it's safe to introduce a dummy/pacifier during tube feeds.

It helps the baby associate the feeling of a full tummy with sucking, preparing them for when they eventually transition to bottle or breastfeeding





# NICU Terminology

## & what it means for you



### *Complications of Prematurity*

Terminology	What it means	Goal	Advocacy
<b>IVH (Brain Bleed)</b>	Bleeding in the brain's fluid spaces (Grades 1-4).	The bleed staying stable or being reabsorbed.	Request "Cluster Care" (doing all tasks at once) to keep blood pressure stable and the room quiet.
<b>Shunt (VP Shunt)</b>	A small tube surgically placed to drain extra fluid from the brain to the belly.	Stable head circumference and "normal" pressure in the brain.	Watch the skin over the "pump" (usually behind the ear). If it looks red, swollen, or the baby is unusually fussy/vomiting, alert the team immediately.
<b>CRP / CBC (Labs)</b>	Blood tests checking for infection markers (White Blood Cells).	Numbers trending back toward the "Normal Range."	Ask: "Is the CRP trending down today?" A downward trend proves the antibiotics are working.
<b>Lumbar Puncture</b>	A "Spinal Tap" to check fluid for infection.	A "Negative" result (meaning no infection in the spinal fluid).	Ask if the baby can have sugar water ("Sweet Ease") or be held in a tucked position for comfort during the test.
<b>NEC (Bowel Issue)</b>	Severe inflammation or infection in the intestines.	Resolving the "loops" in the gut and restarting milk.	Watch for a "shiny" or red-tinted tummy. Ask: "Is the girth (stomach measurement) staying the same?"
<b>ROP (Eye Check)</b>	Abnormal blood vessel growth in the back of the eye.	Vessels maturing normally without needing laser/meds.	Exams are stressful; keep the room dark and avoid handling for an hour after the eye doctor leaves.
<b>PDA (Heart Duct)</b>	A small opening in the heart that should have closed at birth.	The opening closing on its own or with medicine.	Ask: "Is there a murmur today?" A loud, "machinery" murmur often means the duct is still open.
<b>Jaundice / Bili</b>	A yellowing of the skin caused by bilirubin buildup.	Bili levels dropping low enough to stay off the blue lights.	Ask to see the "Bili Graph." It shows how far the baby is from the "treatment line."

# NICU Power Rounds

the roadmap to home



Consultant:  
Date:

<b>What's keeping us here?</b>	
--------------------------------	--

<b>Weekly Goal</b>	
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**Day 1**

Today's Goal	Wins/Setbacks

**Day 2**

Today's Goal	Wins/Setbacks

**Day 3**

Today's Goal	Wins/Setbacks

**Day 4**

Today's Goal	Wins/Setbacks

**Day 5**

Today's Goal	Wins/Setbacks

**Day 6**

Today's Goal	Wins/Setbacks































<b>Notes:</b>
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# Liquid Gold tracker



You are doing a great job!

Date	Time	Total volume (ml)	Method	Hydrated?	Eaten?
			  		
			  		
			  		
			  		
			  		
			  		
			  		
			  		
			  		
			  		

If you can't provide enough milk, the hospital has donor milk and formula ready. Your baby is safe and nourished.

### Troubleshooting your flow

NICU can be stressful but make sure you stay hydrated by drinking 2L water a day and eating properly. Remember you need to care of yourself, in order to care for your baby.

If you're doing all you can and still worried about supply, the NICU feeding team can help. They can even write to your GP to discuss medical support for your production.

# THE FORGOTTEN PARENT

## A gentle guide for partners, dads, and co-parents

### Why this matters

When a baby is in the NICU, the focus naturally shifts to the baby and the Mother.

You are often expected to be the steady one, holding everything together.

But you are a parent too. Your fear, exhaustion, and love all count.

This page is your permission to acknowledge your experience... not just carry everyone else's

### What you might be feeling

**Helplessness:** Watching from the outside and wishing you could fix it.

**The Comfort Gap:** Wanting to support your partner while struggling yourself.

**Workplace Guilt:** Being pulled between hospital, work, and home.

**Outsider Feeling:** Feeling less involved or slower to bond in a medical environment.

**Pressure to Be "Strong":** Being everyone's update point, while no one checks in on you.

### Ways to Connect & Take the Lead

**Skin-to-Skin:** This helps stabilise your baby and regulate your own stress.

**Own a Role:** Choose one care task that's yours, such as nappies, temperature checks, or reading time.

**Stay Informed:** Join ward rounds, ask questions, and understand the plan. It helps restore a sense of control.



### Your Mental Health Matters

NICU trauma affects partners too.

If you notice constant alertness, intrusive thoughts, or a sense of numbness, **it matters**.

Speaking to the NICU support team or a professional is not weakness; it's care for your family.

### Holding Your Relationship Together

**Acknowledge your differences:** Different, doesn't mean wrong. You may cope differently. Both are valid.

**Lower the Bar:** You're both in survival mode. That is enough.

**Small Acts Matter:** A hand squeeze, a coffee, or a quiet presence often mean more than big conversations.

**Daily checkins:** Simply asking each other, "How are you doing right now?" helps you stay connected as people, not just as caregivers.





# PROTECTING YOUR PEACE

## Setting boundaries with visitors during your NICU stay

### Why this matters

Your only job right now is your baby. It's okay to protect your energy.

Well-meaning visitors can be a lot to manage, and setting gentle boundaries is part of coping. You don't have to share updates unless you're ready; taking space is a valid way to care for yourself, and simple messages can help keep others informed without overwhelming you.

### You're allowed to say

"We're not ready for visitors yet."

"Please don't call us for updates — we'll reach out when we can."

"We're keeping things private while we process everything."

"We'd love support — but a meal or errand helps more than a visit right now."

### Bridging the gap after a silent period

"Sorry for the silence, things have been really intense. [Baby's name] is still in the NICU and we're taking each day as it comes. Thank you for your patience and love."

"We know you've been worried. We feel your love even when we can't respond. We're okay...just in survival mode. We'll come up for air when we can."

"You may not hear from us often. It's not because we don't appreciate you — every bit of our energy belongs to our baby right now. We'll update you when we're ready."



#### Quick Tip: Nominate a gatekeeper

Choose 1 trusted person to handle communications. You update only them and they update everyone else. It saves more energy than you can imagine

# WELCOMING YOUR VILLAGE

## Navigating the NICU with the people who love you



### A Gentle Reminder:

Your loved ones care deeply, but this may be their first time navigating the NICU. They might not always find the right words, but their intent is rooted in love and concern rather than negativity. Even when comments feel upsetting, remember they are learning how to support you in this unknown territory right alongside you.

They might say...	They likely mean...	How you can Bridge it
"You are so strong, I could never handle this!"	"I am in awe of how you are showing up for your baby."	"I didn't know I had this strength either, but *Baby's name* makes it easy to keep going. Some days are harder than others though."
"Is the baby going to be okay?"	"I am scared for you and I just want to hear some good news"	"We are hopeful! Every day is a win and right now, baby is working hard and doing exactly what they need to do"
"Everything happens for a reason."	"I'm trying to make sense of something that feels unfair."	You can simply smile and say: "It's a lot to process right now. Thank you for being here."
"When are they finally coming home?"	"I can't wait for your family to be whole."	"We don't have a date yet, but we'll let you know as soon as the doctors give us the green light."



### Not Ready for Visitors?

#### How to love us right now

- Drop off a home-cooked meal
- Help with groceries or errands
- Take care of laundry or household tasks
- Send a kind message that needs no reply

# TINY STEPS TO MILESTONES

counting the inches that lead to the mile

*date:*

*first cuddles*

*date:*

*first skin to skin*

*date:*

*first outfit*

*date:*

*first bath*

*date:*

*first big stretch*

*date:*

*first smile*

*date:*

*first time outside*

*date:*

*first graduation*

*date:*

*first time home*

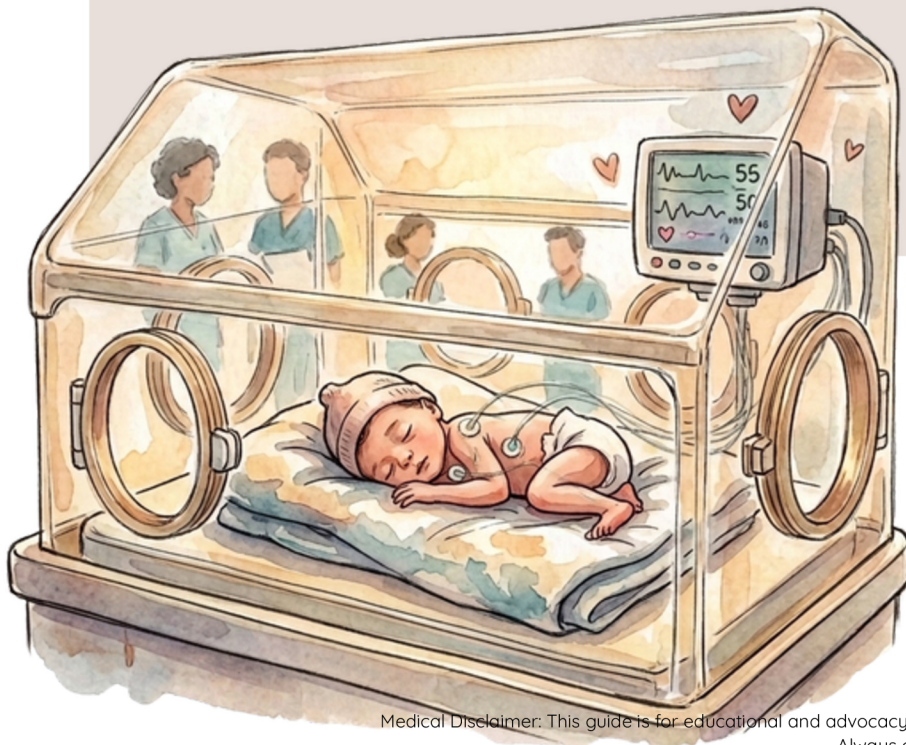


# NICU Visitor Checklist

## Supporting our little one in the NICU

### BEFORE YOU VISIT

- If you have a cold, cough, sore throat, sniffles or have been near someone unwell, please reschedule your visit.
- No strong perfume or scented products as it can be overwhelming for baby.
- Gifts: Soft toys, and flowers are wonderful, but they aren't allowed in the NICU because they can trap dust and bacteria. So please keep them safe for us until we come home



### DURING YOUR VISIT

- You'll need to wash your hands and arms up to your elbows for at least 30 seconds.
- Phone Refresh: Phones carry more germs than we realize. Please use a sanitizing wipe on your phone before coming to the bedside.
- The NICU is really quiet (besides the machines) as all the babies need to heal and rest. Please keep your voice at a soft whisper to help the baby stay calm and grow.
- Baby is still quite fragile, so please be prepared to look and don't touch unless the parents and nurses explicitly tell you that it's safe to do so.
- Trust the Experts: Our medical team are the guardians of this space. If they ask you to step out or follow an instruction, please do so immediately and without question.



# Discharge Checklist

on the road to home



## Baby

- Temperature:** Maintaining 36.5°C–37.5°C in an open crib for 24+ hours.
- Safety:** 5–7 days without a significant desat or bradycardia event.
- Feeding:** Taking 100% required milk volume via bottle, breast, or home tube plan.
- Breathing:** Stable oxygen levels on room air (21%) or home oxygen.
- Growth:** Consistent weight gain (typically 15–30g/day) on the final home plan.



## Parent/Carer

- CPR Training:** infant CPR video and/or mannequin practice.
- Meds Mastery:** Parent has drawn up and administered all scheduled home medications.
- Equipment Training:** Competency in placing tubes, testing pH, or troubleshooting machines.
- Rooming-In:** Completion of 24–48 hours of "Total Care" without nursing intervention.
- Car Seat Challenge:** 90–120 minutes in their own car seat with stable heart rate and sats.
- Safe Sleep:** Understanding "Back to Sleep" and maintaining a clear sleep space.



## Home

- The Baby Station:** A set-up spot with your logbook, thermometer, and a clean area for feeding supplies.
- Milk & Supplies:** A 2-week stash of milk, formula, or fortifier ready in the kitchen.
- The First Visit:** Baby's first followup appointment booked
- Support Contacts:** Phone numbers for the NICU and any specialists your baby needs
- Help & Emergency Info:** A "Who to Call" list for medical problems incl. after-hours numbers and the quickest way to the nearest paediatric A&E



### Bonus Tip:

If you have other kids or pets, a plan for their first meeting with the baby (and who is watching them while you do the first few home feeds).