

- A diary or journal for noting down what happens each day or how you feel.

"I had a diary with me. When you're sat in the hospital day in, day out I found it comforting to write everything down from my own emotions to all that my son Leo went through from day to day (hour to hour in some cases). There's that much going on that it's easy to forget what happened on which day. And it's very true what the doctors say - it is a rollercoaster of emotions and when I look back at my diary now and again all the same feelings come flooding back. I keep meaning to write out my notes properly one day so that I can show Leo when he's older what a brave little boy he was (is)."

For Siblings

- Loads and loads of colouring books, crayons, activity books, puzzles, hand-held games, small scale play toys, etc.
- Their own comforters e.g. cuddly toys or blankets.

For Going Home

- A baby car seat is necessary for when you are discharged.
- A cold water steriliser (using Milton tablets or equivalent) can be very useful for sterilising medicine syringes and tube feeding equipment. Not all babies need the feeding equipment, but most will need medicine syringes. Steam/microwave sterilisers should not be used for syringes or tube feeding equipment.
- Most parents buy a baby monitor so that they can listen out for their baby when they are not in the same room. Some parents also buy a movement monitor (apnoea mat) which alarms if the baby stops moving for a few seconds. The hospital will advise whether your baby has to have one, but even if the healthcare professionals don't recommend it, some parents still use one for their own peace of mind.
- A bouncy chair can be helpful for feeds if you go home with tube feeding equipment, but you could also use the car seat for this.



Practical Tips for expectant parents

This booklet contains some practical hints and tips for parents expecting a baby with a single ventricle heart condition.

This information sheet is designed to give some practical hints and tips for parents expecting a baby with a single ventricle heart condition - parents often ask if there's anything different they should buy, or indeed if they should buy things for their baby. Whether to buy things for your baby is of course a personal decision, however the information below is based on the experience of a number of Little Hearts Matter's member families, and may help you to plan.

Clothes

Some parents like to buy clothes as part of preparing for their baby's arrival. Ideally they should be named to avoid being lost in hospital. For the time in hospital, front-opening, machine-washable garments are vital.

- It is usually a warm environment so the baby is unlikely to need layers.
- Small sized baby-gros which open up completely to be flat on the cot (ie they have poppers down the front and down the inside leg) and have no feet in them - these can then be worn if your baby is allowed to wear clothes in intensive care. Babies often have lines or monitoring equipment on their hands and feet, so these are the easiest to change.
- Front-opening vests are also useful in intensive care and on the ward as babies are checked frequently by medical staff.

"Although the hospital provided certain clothes, it was nice to have our own."

- Some babies are stable enough to wait a couple of days for their surgery, in which case, you may want to dress them in their own clothes.
- Booties or socks (if kept on!) can help the babies' feet keep warm so that the sats monitor (monitor measuring oxygen levels in the blood) hopefully gives a better reading. Socks in a larger size might be useful to fit over the probes.
- A baby towel may be nice to have for the special first bath moment.
- A good supply of easily removable bibs (velcro not ties) so that any vomiting after feeds can be cleaned up more easily without having to completely change the baby.
- Scratch mitts are useful for some babies both to stop them scratching themselves and to stop them from pulling out tubes e.g. feeding tube. If scratch mitts are too big, try very small socks - they sometimes stay on better.
- Find out the hospital policy regarding nappies - many hospitals don't provide them any more, and the last thing you want is to have to go out shopping for nappies instead of spending time with your baby.
- Many families bring a baby blanket to make the cot feel more homely. One of our members is making a crochet blanket for her baby during her pregnancy - helping to keep busy and doing something positive for her baby.

Equipment

- Dummies are often recommended to help babies who are currently unable to feed to remember the sucking action. They may also help to soothe your baby.
- Some parents bring baby lotion.

"On IT U, the babies are under heat lamps to keep them nice and toasty, but the lamps can make their skin a bit dry, so we bought some nice baby lotion to rub into his skin."

- There is usually no need to take bottles as the hospital will provide the right kind of feed and teat if relevant.
- Some families like to bring music or stories for the baby to listen to.

Toys

- A musical toy to put in the cot.
- Some soft toys for the baby to look at (and give the nurses something to prop the oxygen on!).

"Michael had an elephant that regularly used to prop up his oxygen tube - and the nurses made sure the elephant always had the same bandages/dressings as Michael's which we thought was a nice touch...!"

"Gez the giraffe went everywhere with Thomas - even to theatre. He still sleeps in his cot with him now - I like to think Gez is watching over him."

For You!

- A camera (though you may need to get permission from the hospital before you start taking photos).
- Plenty of your own creams and lotions as the hospital environment can be hot and dry, and you will be washing your hands and putting on alcohol gel very frequently, which dries out your skin.

"I know in the grand scheme of things the last two items might seem a bit unimportant, but you need to look after yourself and make sure you are as comfortable as possible too."

- Comfortable clothes and a pillow.