

Leeds Centre for Newborn Care

Information for parents



leeds children's
hospital

caring about children



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Leeds Centre for Newborn Care

Dear Family

We welcome you to our neonatal unit and hope that you find this booklet useful.



Family Integrated Care

The philosophy of care at this Neonatal Unit (NNU) is **Family Integrated Care**. Many parents feel that when their baby is born prematurely or unwell that they cannot give their baby the love and attention that they need. This is not the case, it might just be that you have to care for your baby in a different way to how you expected. Our aim is to ensure that you feel supported and confident to provide as much care for your baby as you feel able and learn how to care for your baby at a pace that is comfortable for you. We want your baby to get the best possible start by them spending as much time as they can with you. This will not only help you to feel much more confident to care for your baby when you go home, but the evidence shows that babies looked after in this way have fewer infections, are more likely to breastfeed, put on weight more quickly, have fewer complications and go home sooner.

This leaflet is intended to help you start orientating you to the NNU experience, so we have put together some basic information we think you may need. We have a lot more information available and we may suggest things you can add along the way.

As your baby starts their stay on the NNU you will be given a booklet called “My Journey”. This is intended to help you and the staff record the skills you have learned in taking care of your baby, and help you see what activities you can participate in to support their care. We encourage you to pick up, read and discuss what is on “My Journey” with the nursing and medical staff.

The Neonatal Service

Leeds Centre for Newborn Care has two sites - one at St. James’s Hospital and one at Leeds General Hospital (LGI).

The LGI unit has intensive care, high dependency and surgical cots. St. James’s provides some intensive and high dependency care and special care. Both hospitals provide transitional care.

Clarendon Wing, LGI



Gledhow Wing, St. James's

Intensive care is for babies that are very sick and need very specialised care.

High dependency is for babies that are a little stronger, but still need a lot of looking after.

Special care is for babies that are better still but still need some special looking after.

Surgical Newborns is where any babies are nursed if they have had surgery in the newborn period.

Transitional care is where mothers and babies can be cared for together.

Some babies will only be cared for in one area, but many will spend time in several different areas and sometimes, other hospitals. In Leeds, the special care and some of the high dependency is provided on the St James's site. Intensive care, surgery and high dependency all occur at the LGI. This means that some babies may move between hospitals to ensure that they receive the best care, in the right place, at the right time.

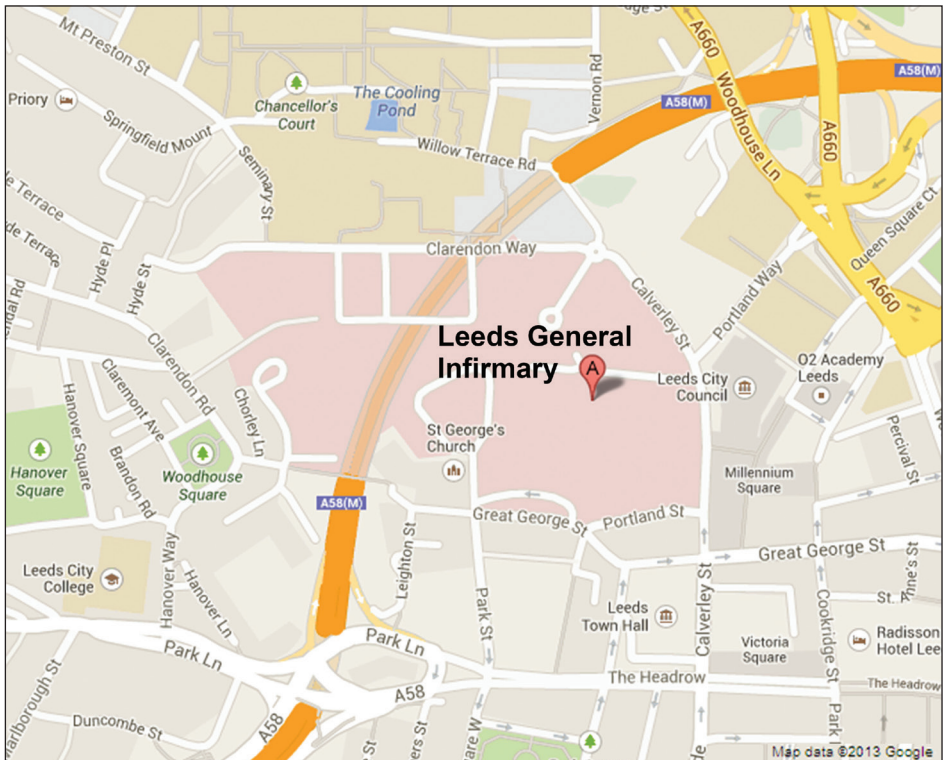
We recognise that this can be challenging for families and we will do our best to minimise this and ensure any transfers are kept to an absolute minimum. Likewise, some infants may move to a hospital outside Leeds. This may be because it is closer to home for them but rarely, it may be necessary to ensure that other sick babies can access the specialist intensive care that only the LGI can provide within Yorkshire and Humber region.

Contact information

LGI Unit

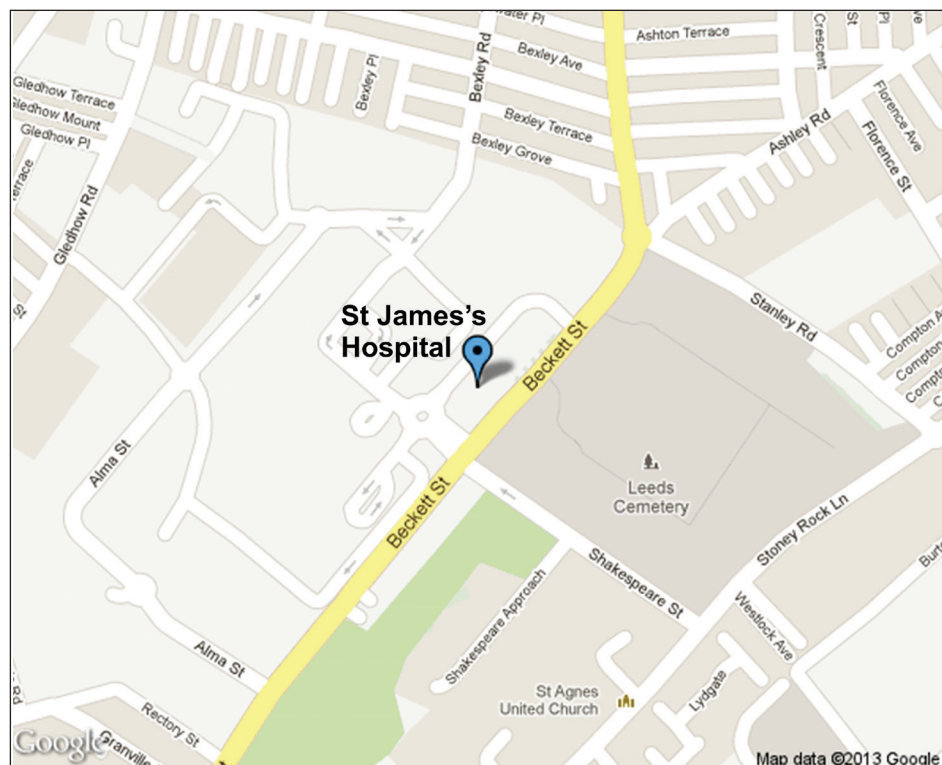
Ward L43, C Floor,
Clarendon Wing,
Leeds General Infirmary,
Great George Street,
Leeds LS1 3EX.

Tel: 0113 392 7443



St. James's Unit

Ward J1, Level 5,
Gledhow Wing,
St. James's University Hospital,
Beckett Street,
Leeds LS9 7TF
Tel: 0113 206 9101



Travel information

Bus - LGI

Many buses coming into Leeds stop on the Headrow (see map). This is a short walk from the hospital.

The Leeds CityBus links the train station, the city centre and the LGI. The service runs every 10 minutes from 06.30am to 7.10pm, Monday to Saturday. On a Sunday, the service runs every 30 minutes. Each vehicle is fully accessible and can carry one wheelchair at any time.

Bus - St. James's

The following buses serve St. James's Hospital:

16, 16A, 42, 49, 50, 50A, 61, 61A, 87

More information on buses can be found at:

www.wymetro.com/howtogetto/Hospitals

Trains

There are main line and local train links into Leeds train station in the city centre which is about a 10 minute walk from the LGI.

Car parking

Whilst your baby is in hospital you are entitled to a free parking permit. Please ask the nurse or ward clerk and they will be able to help you.

Leeds General Infirmary

A multi-storey pay and display car park for patients and visitors is located on Clarendon Way, near to the Accident and Emergency Department.



St. James's Hospital



The main car park for patients and visitors at St. James's is the multi-storey, next to the Leeds Cancer Centre building (Bexley Wing). It is clearly signposted as you enter the hospital site from Beckett Street. It is open from 6am to midnight. Payment is on exit.

Car parking prices (Nov 2021)

Hospital	Up to 2hrs	Up to 3hrs	Up to 4hrs	Up to 5hrs	Up to 6hrs	Up to 7hrs	Up to 24hrs
St. James's	£2.90	£4.30	£5.70	£8.40	£11	£14	£16.40
LGI	£2.90	-	£5.70	-	£11	-	£16.40

Prices are subject to change so please check at:

www.leedsth.nhs.uk/patient-and-visitor-information/patient-information/getting-to-hospital/

Cash facilities

Cashpoint machines are available in Jubilee and Clarendon Wing reception at LGI and Gledhow Wing reception at St James's

Catering facilities

If you are expressing or breastfeeding you are entitled to free meals each day. Please ask a member of staff how you get these as services differ at either hospital. Breakfast facilities along with tea and coffee are available on both units.



LGI

The main hospital canteen is just outside the Neonatal Unit on C Floor of Clarendon Wing. This facility accepts cash and card payments.

There are a variety of food outlets and shops available in Jubilee Wing reception, Clarendon Wing reception, locally and in the city centre.

There is a Tesco Local just outside the hospital grounds, close to Jubilee Wing main entrance.

St. James's

The main hospital canteen is on the ground floor of Gledhow Wing, the same building that the baby unit is in. There are also a number of food outlets and vending machines. Cash and card payments are accepted.

Financial support

Having a new born baby on the NNU brings a lot of extra expense, including travel costs, parking, extra child care and missed days at work.

We recognise that this is a problem faced by many parents. Although we are unable to provide financial support, we can signpost you to several other resources. Some help is available to most families even if you are working. It is important to ensure that you are receiving all the assistance and entitlements available to help you through this difficult time.

Basic facts about the benefits or assistance families can receive, eligibility to claim, and where you can find more information can be found on the Bliss website **www.bliss.org.uk**.

This includes

- Maternity and paternity pay
- Child benefit and tax credits
- NHS benefits
- Help with housing costs and bills
- Help with travel costs
- Family Fund
- Financial information for those on a low income
- Help from charities and other groups

Although the information in this section is correct at the time of writing, benefits are always subject to change. For the latest information on benefits, go to **www.gov.uk** or visit **www.turn2us.org.uk** where they may be able to help you access further benefits and grants. If you have any difficulty accessing this information, please ask a member of staff.

The Neonatal Unit

The next few pages will tell you a little bit about what to expect when your baby is in the NNU. This only provides basic information - we can give you more information as your journey progresses.

The important thing to always remember is that we are here to help you take care of your baby. Although this may sound a bit odd, many parents feel disconnected and helpless when their baby is in special care. Please talk to your nurse about this - **you are essential to your baby's care in a way no-one else is.**



The nursery can be a busy place but never feel that you are "in the way" or things are too busy for you to ask a question. We will show you all the different ways that you can care for your baby, to help you gain confidence and bond with them.

The first few days

We try to offer parents who are having a baby that will need special care, a visit to the unit before baby is born. This can be helpful as many people find the first time they come to see their baby quite overwhelming.

If your baby has been born early (premature) they may be in a specially warmed cot called an incubator, or a platform with an overhead heater, if baby is a bit bigger. The incubator allows your baby to receive the warmth and humidity that is necessary in the first week after birth.

So that we can closely monitor your baby they may only wear a nappy at first but this will change.



There may be a lot of monitors and drips attached to your baby to help them get better and stronger. Most babies will have a thin, soft tube in their nose or mouth (nasogastric or orogastric tube) in order to give milk or medicine. Some babies may need intravenous treatment, this could be through a drip into their umbilical cord or veins in their arms or legs.

Some babies require additional help with their breathing through a variety of different methods. The nurse looking after your baby will explain this in more detail.

Babies over 28 weeks gestation will have a daily wash using a special mitten, like a baby wipe, covered with Octenisan, a cleaning solution which helps them fight infection.

Coming to see your baby

Both of baby's parents or one parent and one named support person are welcome to visit their baby any time of the day or night. Spending most of the day with your baby in hospital can be tough, so you can share this time with partners or other relatives/people in your baby's life if you'd like to.

Our visiting policy for other family and friends is subject to change at the discretion of hospital management. Please speak to the staff looking after you and your baby to find out what our current visiting policy is.

Due to the space available in our nurseries and the need for constant access to the life saving equipment, only two adult visitors are allowed in each bed space at one time.

Children under the age of 16 are not normally able to come into the NNU unless they are the baby's brother or sister, or there are special circumstances. Talk to the lead nurse about this.



Ward rounds

We have a policy of very open discussion with parents. Consultant ward rounds happen every morning at 9.00am so that the doctors and nurses can review your baby's progress and care. We would encourage you to come to the ward round. It is an ideal opportunity to be with your baby so that you can let the team know how you feel your baby is doing and the medical or surgical teams can update you and explain how your baby is getting on. Your presence on ward round is also a way for you to contribute to plans for your baby's care and communicate with the nursing and medical team. It is an opportunity for you to be the voice for your baby.

If you are unable to attend, your baby's nurse will be able to update you on your baby's progress and there are always doctors around too.

We prefer not to ask parents to leave the clinical area during ward rounds when other babies have some of their clinical care needs discussed. We want to encourage all parents to spend as much time as possible with their baby. Consequently, we ask all parents to respect the dignity and confidentiality of other babies on the unit by not approaching another baby's cot without permission, or sharing any information that you might overhear. If you do not wish your baby to be discussed when other parents may be present on the ward, please make a staff member aware so that we can make alternative arrangements.

As part of your baby's care they may need assessment and care from other health professionals, such as physiotherapists, occupational therapists, dieticians or speech and language therapists. The specialists will show you additional ways to help care for your baby and aid their recovery and development. If you have any questions about this please talk to your nurse or doctor.

Please ask if there is anyone you would like to talk to about your baby's care. As well as talking to doctors, staff can arrange for you to discuss any issues with a ward Sister or Matron. If you wish to see your baby's medical records this will require a formal request via Information Governance. This can be accessed via the trust's webpage.



Having a baby in the neonatal unit can be a stressful time. We understand that and we are here to try to make it easier for you. There will be good days and bad days and things can change quickly, and we appreciate how difficult that can be. The neonatal staff are here to support you and can refer you to a counsellor, psychologist or chaplain if you feel you need this. Many parents also find that talking to other parents on the unit or those who have been through the NNU experience can be helpful.

Notice boards around the unit will advertise parent coffee mornings, and sometimes 'veteran' NNU parents volunteer to come and chat. Please talk to staff if you feel you need more support.

Things to bring to the unit for you and your baby:

- Small cuddly toy(s) or comforter for your baby's incubator/cot
- Muslin square - we will give you a muslin square to help wrap your baby during transfers, weighing or bathing so that they can feel safe and secure, but it is helpful to have a few of them to hand
- A loose top for you, to help you have Kangaroo Care with baby
- A small hand mirror to help you see baby's face when you are holding them
- A notebook and pen to help you write down questions for the doctors, or make lists of things to remember.
- If you think you would like your child to have a dummy or soother discuss with staff as to whether it may be suitable
- Pictures of your family for your baby's cot space or drawings/pictures that siblings may wish to give to baby.



Nappies

We do ask that you provide nappies when your baby is over one kilogram in weight. Most supermarkets do their own brand of premature baby or low birthweight nappies - usually 1-2.5kg. Very small nappies are also available in supermarkets - they are called micro or size 0. Some pharmacies are able to offer premature nappies for free but this depends on location and local availability.

Clothes for your baby

For the first few days of your baby's admission we have a small stock of nappies and clothes, however we would ask if you would bring in vests and babygrows.

Try to get size appropriate clothes - if they are too big it is sometimes difficult for baby to maintain their temperature.

Pop 'N' Grow is a charity providing free premature baby clothes - usually an incubator vest, babygrow and hat in an appropriate size for your baby. The clothes are specially designed to work around IV's and monitoring equipment. They are on Facebook and at www.popngrow.co.uk.

Just email them with your name, your baby's name and weight and the name of the hospital you are in. They will send a package to you.



Other places to buy premature baby clothes include:

www.earlybaby.co.uk

www.auntymbettys.co.uk

www.tillytally.co.uk

www.cheekychumsonline.co.uk

www.pumpkinpatch.co.uk

Supermarkets like Asda, Tesco and Sainsbury's have some smaller clothes available in store and Mothercare at Boots do premature baby clothes for 3-5lb babies.

Facilities in the ward

There are some facilities at both the LGI and St. James's that all parents are free to use. Both wards have a small kitchen with tea, coffee, milk and cereal as well as a microwave to heat up your food.

Please use the lockers and coat hooks provided for belongings that you do not need while you are on the NNU.

There is a parent's sitting room and a sibling room with toys and activities. 'Supersibs' is a programme run by volunteers which supports parents by providing supervised play sessions for siblings of babies on the NNU. Please ask when these are being held. Outside of these sessions, siblings that come to the unit must be supervised in the sitting room at all times.

There are two parent's bedrooms at both the LGI and St. James's. These are primarily used for families who are either preparing for home or whose baby is very sick. If you wish to stay at the hospital with your baby please speak to staff about available facilities.

Infection prevention

Preventing the spread of infection is very important in any hospital, and especially so in any area looking after small, sick babies.

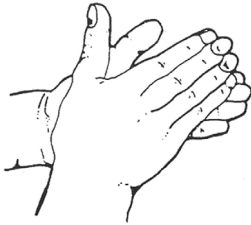
We therefore have a very strict infection prevention policy. If you notice people not following the policy, you are welcome to ask them why not, or talk to the nurse in charge. People may also ask you if you do not follow the policy.

Please leave coats on the hooks provided.

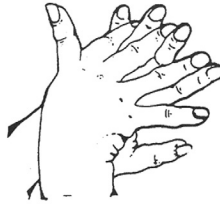
Do not bring anything you do not need to care for your baby into the nursery.

Wash your hands thoroughly with soap and water at any of the sinks when you arrive on the ward, and on entering a new area.

Effective Handwashing



1. Palm to palm



2. Right palm over left dorsum and left palm over right dorsum



3. Palm to palm with fingers interlaced



4. Backs of fingers to opposing palms with fingers interlocked



5. Rotational rubbing of right thumb clasped in left palm and vice versa



6. Rotational rubbing, backwards and forwards with clasped fingers of right hand in left palm and vice versa



Please do not touch anything that does not belong to your baby.

Whenever you have touched anything, or are about to, please use the antibacterial hand gel provided.

Please do not come to visit if you have a cold, 'flu-like symptoms, vomiting or diarrhoea. If you are unsure, please telephone and speak to the nurse looking after your baby. Do not allow visitors that have any infectious illness or symptoms to visit.

Who is looking after my baby?



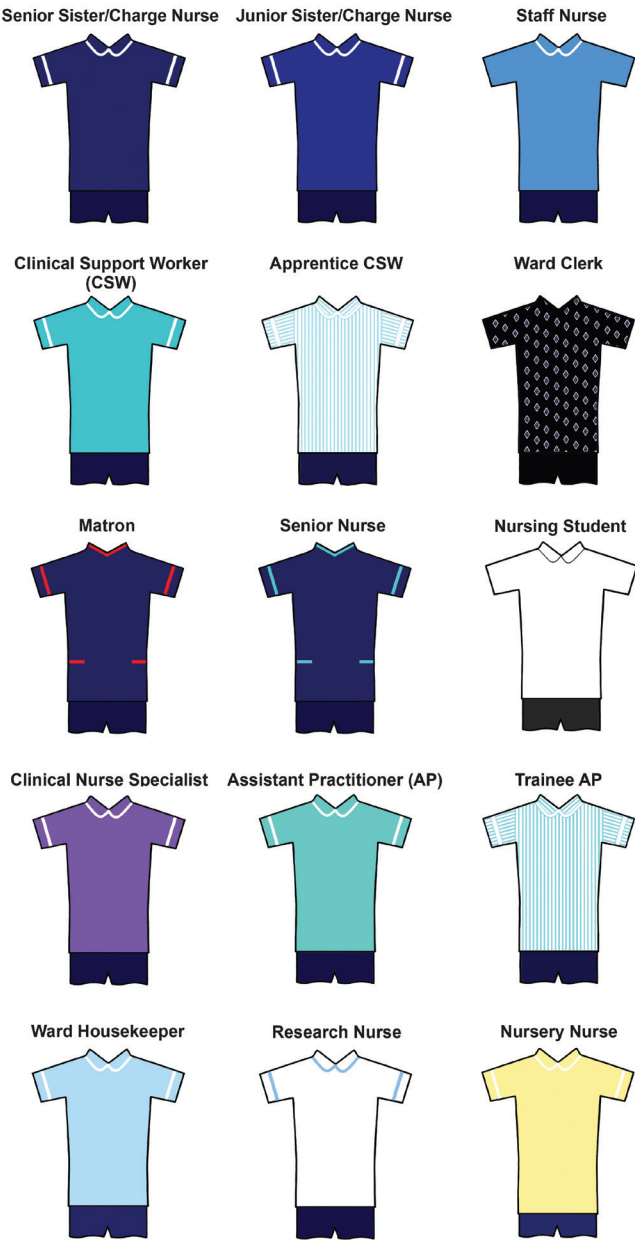
When your baby is admitted to the NNU you will hear lots of unfamiliar words and meet lots of different health professionals. There is an electronic staff photo board so that if you forget someone's name you should be able to find them on the photo reel.

The nurse that first looks after you and your baby is most likely to be your named nurse. Although they will not always look after your baby when they are working, they will always follow your baby's progress and be there to help and support you.

The doctors work as a team so you are likely to meet several different faces. Don't feel awkward about asking for names so that you know who is looking after your baby. The doctors will try to update you every day and you should see a consultant every week just to catch up. This will be more frequent if your baby is in intensive care. If you haven't managed to speak to your consultant and would like to, then just ask your nurse and they will organise this.

There are lots of different uniforms to get used to as well. Most of them are pictured on the next page.

These are a few of the uniforms that you may come across.



Caring for you

If you have had your baby in Leeds you will probably stay in hospital for a few days. Often the wards will try to accommodate your partner too although this is not always possible.

After you are discharged, accommodation may be available for you if you live some distance away. This is in the parent's house called Eckersley House which is located in the grounds of LGI, opposite the Children's Hospital entrance. Talk to your nurse about this. Space is limited so the rooms are carefully managed.

Caring for your baby

Many parents feel very helpless when their baby is admitted to a NNU.

If your baby is very tiny, very early or very sick, they may need complex, highly technical medical and nursing care. It is important to remember that you have a very important role in your baby's care. Oxytocin is a hormone that you and your baby make when you feel relaxed, secure and loved. Babies benefit from high levels of oxytocin as it helps their brain to grow and helps them develop into a happy baby. Oxytocin is also really important in reducing your stress hormones and encouraging your milk to flow well. There are plenty of things that only you can do to increase your baby's oxytocin levels. These are essential for their growth, healing, recovery and development. To help you make a start these are a few suggestions of things you can do.

- **Watch your baby** (this is an opportunity to get to know your baby and how they communicate stress, pain, or when they are ready to engage. Their reactions can guide us to understand what they need in their own way, this ensures that we can adjust their care sensitively)

- **Comfort holding** (Positive touch is a way of communicating love and reassurance, and can help soothe and calm.)
- **Hear your voice** (talk and read to your baby in a soft voice)
- **Shade their eyes from the light**
- **Express your breast milk**



As well as being supported by the staff to help you care for your baby, each weekday we have teaching sessions focussing on all aspects of the Special Care journey which we encourage you to attend to support your knowledge and understanding about your baby. These sessions will be displayed on the Family Integrated Care board. Please ask your nurse if you have any questions or if you require any further information.

Developmental care

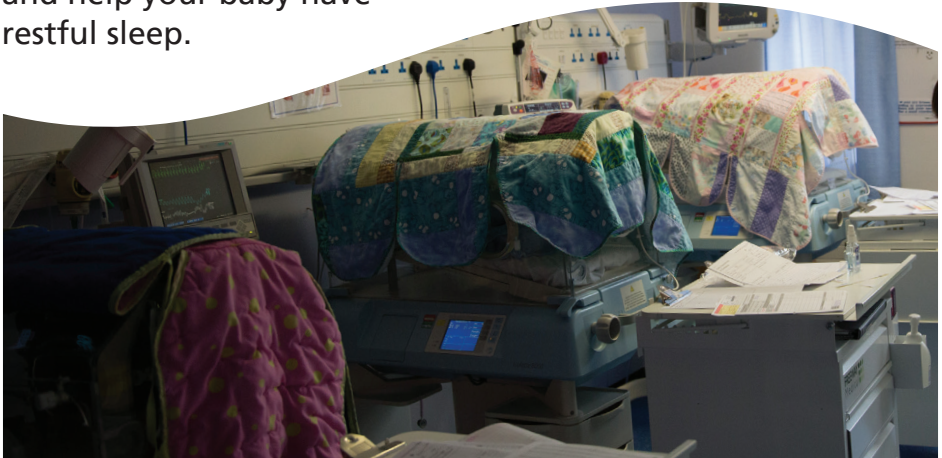
NNU is clearly a very different place for a baby than their mother's womb, and this has the potential to affect how well babies grow and their brains develop. Developmental care is a range of interventions to help overcome this by minimising the stress the neonatal unit has upon your baby. It also helps to support their general well-being, protects sleep and helps to promote normal muscular development.

Whilst your baby is on the neonatal unit you can help to implement these strategies alongside the nursing team.

Light and sound

A preterm baby's eyes and ears are vulnerable to bright light and loud noise, and their brain needs lots of undisturbed sleep to mature.

On the neonatal unit we try to keep the light low as much as possible. If your baby is nursed in an incubator you will see we use incubator covers and some cots have canopies. This is to help reduce the amount of light directly reaching your baby and help your baby have restful sleep.



Your baby will also have more settled periods of wakening in low light conditions, so there is a better chance of them being able to look at your face and interact with you.

You may notice your baby reacting to different sounds and become disturbed by loud noises. Noise in the nursery should be kept to a minimum and we ask staff and parents to talk quietly, as well as avoid making sudden noises such as putting items on top of incubators or shutting their doors quickly.



Babies enjoy it when parents talk to their baby in a low soothing tone - this will help your infant to settle as they already know your voice. Please feel free to bring in books to read to your baby.

Positioning

Positioning is what we do to make your baby feel comfortable and to help support their developing posture and movements. The position that is best for your baby is the one they are most settled in.

You will see your baby nursed in a positioning nest or with boundaries and rolls around them to help support their posture. Boundaries also help babies feel snug and secure as they can brace their feet and hands against them, similar to how they would have done in the womb. The nursing staff will demonstrate how you can use different positioning techniques and make nests so you can be involved as much as possible in your baby's care.

Positive touch

By touching your baby you can help them remain calm and settled. You can do this to help them during procedures carried out during their care e.g blood taking. We feel parents are the most important givers of positive touch as you will become the most consistent observers of your infant. Using warm, clean hands, you can start by offering your baby a finger for them to hold, or by cupping their feet, body or head in your hand. As you begin to feel more confident you will be increasingly able to comfort them by cradling their head or feet in your hands or resting a hand over their bottom or shoulder, keeping your hands still and firm. Try not to touch baby too softly or tickle them gently as this can overstimulate and unsettle them. The nursing team will help show you these techniques as you become more confident.

If you would like further information on any aspect of developmental care leaflets are available on the unit or feel free to speak to any member of the Neonatal team.

Kangaroo Care

Kangaroo Care is care of the preterm/sick baby through skin to skin contact with the mother and father. It is also used on full term babies to promote health and wellbeing.

Receiving prolonged medical care for the pre-term and sick neonate is important. Kangaroo Care, however, is an effective way to meet the baby's requirements for warmth, protection, safety and love.



It's main aims are to:

- decrease stress levels in babies and parents
- reduce pain responses in babies
- normalise temperature, heart rate, respiratory rate and stabilise oxygen levels
- increase weight gain
- promote bonding
- improve parental confidence
- promote increased milk production and breastfeeding success
- increase the probability of early discharge.

When can Kangaroo Care begin?

Even if your baby has very complex needs e.g monitoring equipment, a breathing machine and/or fluid infusions they may still be able to have Kangaroo Care. In fact babies who are in Kangaroo Care tend to be more stable. Whether your baby should have kangaroo care will be based on whether the nurses or doctors feel it is safe for them to transfer out of their cot or incubator and the staff support you will need.

How is Kangaroo Care done?

In Kangaroo Care, your baby will only wear a nappy and is placed on your chest in skin-to-skin contact. They may be secured with a stretchy wrap. If preferred, baby can go inside a stretchy top (t-shirt).



We also have some patient gowns which are front opening and baby can be covered with a blanket or sheet. The head, turned to one side, should be in a slightly extended position. This head position keeps their airway open.

Their hips should be flexed and the legs in a frog like position. The arms should also be flexed. Baby's tummy should not be constricted and should be somewhere at the level of the top of the holder's tummy so they have room for abdominal breathing. It is beneficial for baby to be in Kangaroo Care for at least 30 minutes to begin with and then an hour or longer. It is less stressful for baby the longer they are in Kangaroo Care.

Feeding your baby

We know that babies fed with breast milk are better protected against diarrhoea, gastroenteritis, ear and chest problems, and are less prone to asthma and eczema. As they grow older, breastfed babies are at less risk of diabetes, heart disease and obesity.

When a baby is born prematurely, or is very small or unwell, we encourage mothers to feed their babies breast milk, as we know that it has a lot of additional benefits for the baby. It has been found that breast milk will work better than most medicines to protect them against illness and infections. It also helps their body to mature, particularly the digestive system and the brain. In the early days when baby may be poorly they can still have small amounts of your milk as mouth care which provides some protection against infection, and babies seem to like the taste.

Even if you did not plan to breastfeed your baby, it is really important to give them your expressed breast milk while they are in hospital, in order to give them the best chance to progress.

Expressing - getting started

To get started, ask a member of staff to show you how to hand express as soon as possible after delivery. Try to express 8-12 times over each 24 hour period. Leave no more than a four hour gap between each session in the day and a maximum of six hours at night. Always be sure to express at least once overnight to encourage and protect your milk supply.

The amount you produce may seem very small to begin with, often less than 1ml in the first few goes, but this is normal and your volumes will soon start to increase over the next few days if you express frequently. Staff will carry out four expressing assessments over the first two weeks to make sure that you are progressing with your supply. The higher the volume you manage to express in the first two weeks, the better your long term milk supply will be.

We have electric breast pumps that you can use while you are on the NNU. We can give you a hand pump for when you are at home. Staff can give information on where you can hire or purchase electric pumps for home. Your nurse or midwife will also be happy to give you more information or support - please ask.

For more detailed information about expressing and breastfeeding please read the leaflets '**Off to the best start**' and '**Expressing breast milk when your baby is on the Neonatal Unit or Transitional Care**'.

In some cases, while you are establishing your breast milk supply we may, temporarily, need to give your baby an alternative milk. If your baby is very premature we may ask for your consent to give them 'Donor Breast Milk'. Similar to when a person donates blood, the process of obtaining Donor Breast Milk is through a strict screening and pasteurisation process and we would not give it to your baby without explaining the medical need for this and gaining your full consent. In some cases we would ask if we could give formula to your baby, but only if we believed it to be in your baby's best interest, and with full discussion with you. However, if you decide that you do not want to express or breast feed your baby we will support you with the decision you make - your baby will still receive the best possible care.



A mum's view of having a premature baby

If you ask any mum of a premature baby, you will find that one of the most commonly felt challenges while your little one is in Intensive Care or Special Care is that of actually 'feeling like a mum'. It feels really unnatural to have given birth to your baby and yet it is someone else or rather a team of people who seem to be more involved in your baby's care than you.

In those first few days of adjusting to your baby being in an incubator in a hospital unit, it can all be extremely overwhelming and a lot of mums can feel lost or even 'surplus to requirements'. However, there are two key aspects of your baby's care that you and only you can properly provide. The first is 'Kangaroo Care' - also known as skin-to-skin care. This is a crucial part of both your little one's development and of your journey into 'feeling like a mum'. After all, what can be more natural than holding your newborn baby in your arms?

For many mums of premature babies this opportunity may not arise immediately; for us it was when our little 27 weeker, Max, was six days old. It may be in the first few days, it may be a bit longer, but when the team looking after your baby offer you the chance to have your first cuddle, there can be all sorts of emotions; excitement, anxiety and even fear. How do I hold this very, very tiny little person who weighs less than a bag of sugar? What do I do about all the wires?

Well, from my experience, that first cuddle when our little boy was six days old was the first time I fully smiled and relaxed since my waters had broken nearly two weeks earlier. He was on CPAP at the time and had on one of those especially tiny nappies (the ones before you even get in to the tiny pampers range) and I slipped him inside my dressing gown and cuddled him against my chest. Yes, he was very scrawny, there were wires everywhere – but it was a special moment and one which neither I nor my husband will ever forget.

The following days and weeks became marked by the time of day when I could look forward to our skin-to-skin cuddle. I had a special blanket I would always use and would always make sure that I was wearing a suitable top into which I could slip my little boy against my chest. The benefits weren't just one-sided; while I got my regular dose of 'feeling like a mummy', our skin-to-skin time also gave Max a bit of a boost to his oxygen levels. It was something quite special to see – while his O² saturation levels rarely crept above 88 or 90% most of the time, he would be 'pinging' at 99 and 100% when held against my chest.

Of course there were also days when he wasn't well enough to 'come out for a cuddle'. These very special little babies are extremely sensitive and a tiny increase in levels of feeds or an attempt to go for an extra 30 minutes off CPAP can sometimes be enough to knock them back a few steps. It's during these times that sometimes the cuddles will have to wait for another day.

That's pretty tough, particularly when your cuddle time is all you're looking forward to that day – but unfortunately that's the rollercoaster emotional ride of this journey so often described as 'Two steps forward and one step back'.

The other opportunity to be the unique provider in your little one's journey through ICU, HDU and SCBU is your breast-milk. I should probably say that personally I have always been a bit non-committal on the breastfeeding issue; if it happens it happens and I certainly have no personal problem with giving your baby formula. Of course at just 1lb 13oz, Max was too small to even attempt to breastfeed but I knew instinctively that I wanted to try and express breast milk. The first attempt was fruitless but the second was successful and it was pretty amazing to experience my body doing something like that.

When it came to providing breast-milk for Max, a bit like the Kangaroo Care, I felt that the benefits were reciprocal; while the milk that I could produce for Max would help strengthen his immature gut and help him grow, my sessions sitting at my breast-pump gave me something to do and made me feel like I could really play my part in his development. It was another way to structure my time during those early weeks and months, with 3-4 regular expressing sessions, including getting up in the middle of the night. I was pretty obsessive about my breast-pumping rituals of writing down all my times and amounts, sterilising my equipment, labelling up the

bottles and storing them away in an organised way in various freezers.

Once he was a bit bigger, we would try each day to encourage Max to latch on but he never quite managed it.

By the time Max came out of hospital, three days after his original due date, we had three freezers full of milk ready for use over the next few months and I actually felt doubly lucky when it came to feeding; Max got the benefit of breast-milk thanks to the months of expressing and yet he took it from a bottle, allowing Dad to enjoy feeding him too.

So with all the ups and downs of three months in hospital including three different hospitals and emergency surgery, I definitely felt like Max and I had been through it all together. For me, Kangaroo Care and expressing milk really helped me 'feel like a mum' and meant that we really knew how to look after our little one by the time he was ready to come home.

Cally Albrecht

*Mum to Max,
born on 24 October 2009, at 11b 13 oz,
surviving twin to brother Louis Albrecht.*

Screening

All newborn babies undergo a series of screening tests or health checks. Most babies will be perfectly fine and the tests will all be normal but if a test does pick up something the benefits of finding and treating it early can be enormous.

Every baby will have a newborn check where he or she is examined from head to toe. In Leeds we also check your baby's oxygen levels with a little monitor on their feet. This takes a couple of minutes and helps to rule out heart problems.

A newborn blood spot test will be taken for all babies on day five of life. Some babies who are born early will have this repeated at day 28. This looks for some rare conditions where early treatment really benefits baby. Before leaving hospital all babies should get a hearing test as well.



For more information visit: www.nhs.uk/Livewell/Screening/Pages/Newbornscreening.aspx or pick up a leaflet from our 'information highway'.

Journey box

When your baby is admitted to the NNU, the nurse caring for your baby will show you around the unit and explain where things are and a little about some of the things you need to know. You may not remember everything so please keep asking - we understand there is a lot to take in.

The nurse will also give you a 'journey box'. This is a box filled with various things including information, and some diary pages where you can make notes and add photos about your baby. The nurses will write and put in pictures for you when you cannot be here.

Support

Having a baby that has been born too early or sick can be a very stressful experience. Parents experience all sorts of different emotions that can be very hard to deal with.

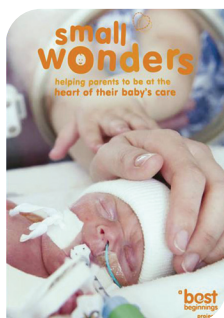
As health professionals caring for your baby, we understand this and are here to help you. Your baby needs you to be strong and healthy to aid his or her recovery. As well as talking to your baby's nurse there are lots of other people and places that you can go to for help. We have a lot of written information available that you can see around the unit or ask for.

Your midwife on the ward or at home, or your GP can support you and there is also a psychologist that you can arrange to meet, either as a one off, or for several sessions to help you through the difficult times. This is confidential so don't be anxious about what you say. The nurses can arrange this for you.

Best Beginnings is a baby charity that have lots of information on their website that may help.

www.bestbeginnings.org.uk

Baby Buddy is an app made by Best Beginnings which you may have downloaded in pregnancy. Although a lot of the information gives advice about normal pregnancy and the



postnatal period, it also introduces you to a wide range of informative film clips which cover aspects of having a baby in a neonatal unit. If you do not own a phone we have a stock of DVDs which have the same information on them. Many parents find the information on the app very useful, so please take some time to watch the film clips.

Bliss is a premature baby charity. They have volunteers who come into the unit on a regular basis.



These are parents (usually mums) who have had a premature baby themselves. They are very happy to sit and chat to you and this is often really comforting.

Just ask when they will be next visiting.

Bliss

for babies born too soon,
too small, too sick

Bliss helpline: Tel: 0500 618140
(9am-9pm, Mon - Fri)

Email: hello@Bliss.org.uk

Web: www.bliss.org.uk

The website provides lots of useful information and there is also a message board where you can 'chat' to parents that have/had babies on neonatal units.

They also have lots of support groups in the area which you and your family can visit to get support from parents who have been through the same experiences as yourselves. Up to date details of meetings in your local area are available on their website.

www.bliss.org.uk/our-community



Moving hospitals

If you have come from another hospital or if your baby was planned to be delivered in Leeds but you come from another area, your baby will move back to your base hospital when they are recovering and strong enough. This will be discussed with you. Some families find this move difficult as they are so used to the care, the staff and the set-up of the hospital they are in.

In Leeds we are often asked to provide specialist care for sick babies so it is sometimes necessary to move your baby when he or she is well enough. This will hopefully be closer to home, but in exceptional circumstances it may be necessary to move your baby a little further. This is only done if absolutely necessary and when there are no other options. Your baby will not be moved between hospitals unless we are sure it is safe to do so. If you are able to, we advise you to visit the unit that you will move to before your baby goes. If you would like to do this please speak to your nurse.

Information about each baby unit in the Yorkshire and Humber region should be available on the internet at www.yorkshirehumberodn.nhs.uk/neonatal

If you live in Leeds your baby may move between the LGI and St. James's. Moving from St. James's to the LGI is usually for more care or investigations. Moving from LGI to St. James's is often because your baby is stronger and healthier. St. James's specialises in babies born nearer to their due date and babies that are getting ready to start planning for home.

Please ask your nurse to see if we can arrange for you to visit the other unit before your baby is moved. You will see a lot of familiar faces when you go as all staff work at both hospitals.

Moving your baby to another hospital is done by a specialist team of nurses, doctors and ambulance drivers who do this all day and every day. They have very special equipment to ensure a safe and comfortable journey.

Sometimes you are able to travel with your baby, other times you will need to find your own transport. This will be discussed with you.

The transport team is called Embrace.



Registering your baby's birth

By law you need to register the birth of your baby within six weeks so there is no big rush to get it done immediately.

Where can I register the birth?

If your baby was born in Leeds you can register the birth at the One Stop Centre in the city centre.

Leeds City Centre One Stop Centre:

2 Great George Street, Leeds LS2 8BA

Details of how to make an appointment are on page 44.

There are also One Stop Centres in the following areas:

Armley: Stocks Hill, Armley, Leeds LS12 1UQ	Middleton: St. George's Centre, St. George's Road, Leeds LS10 4UZ
Beeston: 190 Dewsbury Road, Leeds LS11 6PF	Morley: Town Hall, Queen Street, Morley, Leeds LS27 9DY
Chapeltown: The Reginald Centre, 263 Chapeltown Road, Leeds LS7 3EX	Osmondthorpe: 81a Wykebeck Mount, Leeds LS9 0JE
Garforth: Lidgett Lane, Garforth, Leeds LS25 1EH	Otley: Nelson Street, Otley, Leeds LS21 1EZ
Harehills: The Compton Centre, Harehills Lane, Leeds LS9 7BG	Pudsey: Town Hall, Robin Lane, Pudsey, Leeds LS28 7BL

Rawdon (Aireborough): Micklefield House, New Road Side, Rawdon, Leeds LS19 6DF	Seacroft (South): 90-95 Moresdale Lane, Leeds LS14 6GG
Rothwell: Civic Buildings, Marsh Street, Rothwell, Leeds LS26 0AD	Wetherby: 24 Westgate, Wetherby, Leeds LS22 6NL
Seacroft (North): Unit 8, Seacroft Green Shopping Centre, Seacroft, Leeds LS14 6LU	

If you prefer, you can register the birth outside Leeds. The Registrar will send the details on to us but you will need to wait for the certificate to reach you by post.

Who can register the birth?

Either the mother or father can register the birth if they were married to each other at the time the baby was born. If you are not married both mother and father should attend to register the birth.

The mother may register the birth alone but will not be able to record father's details in the register. If the father's details are not recorded in the register, then he will not have any legal parental responsibility for the baby. It may be possible to add the father's name at a later date.

Making an appointment

Ring (0113) 222 4408 (between 8.00am and 6.00pm) to make an appointment to register your baby or for more information.

How long will it take?

The registrar aims to offer you an appointment within five working days and to see you within 10 minutes of your appointment time.

Registering a birth takes up to 30 minutes. Remember to leave extra time for parking. If you arrive more than 15 minutes late for your appointment they may not be able to see you.

More details can be found at:

Email: Register.office@leeds.gov.uk

Website: www.leeds.gov.uk

One stop centres: www.leeds.gov.uk/council/Pages/One-Stop-Centres.aspx

You will be given one copy of the certificate and you can buy more copies if you wish.



Research

Our neonatal service strongly believes that participating in trials and research about babies is really important. We believe that being at the forefront of research will help our babies get the best and safest care they can.

During your baby's admission you may be asked if you will allow your baby to help us with our research. If we do discuss this with you someone who is involved in the research will spend some time talking to you about it. You are free to ask any questions that you have and they will leave you with some written information. You and your partner can then decide if you want to participate. You are free to ask the person to come back and ask anything you want to about the research. If you do agree to participate please remember that you can change your mind at any time.

Regardless of whether or not you decide to take part in any trials, your baby's care will never be affected. We will always aim to provide the highest quality, safest care we can.

Some of the trials we have participated in:



The staff on Leeds Centre for Newborn Care want to support you and your family to have the best possible experience during your baby's stay. However, if you are unhappy with the care you have received, please ask to talk to the doctors, ward sisters or matron about this.

You may feel more comfortable contacting our Patient Advice and Liaison Service (PALS). PALS can help give you advice about you and your baby's care. It is a confidential service that can help you complain if you are unhappy about the care you have received and help us improve.

Contact PALS on **0113 206 7168** or **0113 206 6261**.

Email: **patientrelations@leedsth.nhs.uk**



Notes

Here's some space for you to make notes and jot down things that you want to ask us about



What did you think of your care?

Scan the QR code or visit bit.ly/nhsleedsfft

Your views matter



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