NHS
University Hospitals Sussex
NHS Foundation Trust

Welcome to the Trevor Mann Baby Unit

Family Guide

Patient information

Contents

Welcome to the Trevor Mann Baby Unit

Congratulations on the birth of your baby!

We realise that this is a difficult time for you, but we hope that this information will help reduce some of the stress involved in having your baby on the Trevor Mann Baby Unit [TMBU].

We are a surgical Neonatal Intensive Care Unit [NICU] that provides specialist care for babies who are unwell. This includes babies that are born prematurely and term babies who are unwell. As a surgical unit, your baby may have been transferred to our unit because they require surgery. Our NICU has all the necessary facilities and staffing to deliver high quality and up-to-date intensive care to newborn babies and supportive care to babies and parents during the stages of recovery and growth.

Your baby is here because they need extra medical, surgical and nursing care. If your baby has come to TMBU because they require specialist care, our aim is to transfer your baby back to your booking hospital or one closer to home as soon as is appropriate.

We are continually involved in local, national and international research projects. As a result of many parents consenting to their babies' taking part in such research, we have been able to constantly improve neonatal care. If your baby is a suitable candidate for one of the research projects we are involved in, a member of the research team will discuss the option of participation. It is completely voluntary, but we will give you all the information so that you are able to make an informed decision.

This welcome booklet will provide you with an overview of our neonatal unit and the care we provide. We hope you will use it as a reference guide throughout your neonatal journey, alongside the unit app and staff support.

What you can expect from our staff

- We are here to help and support you as a family, keeping you updated on the progress of your baby.
- We will be honest and open, including you as partners in your baby's care.
- Our aim is for you to be confident and skilled in caring for your baby while on the neonatal unit.

What we expect of parents

- We ask that you work with us as partners in the care of your baby. This means being as present as possible to care for your baby, attending ward round discussions and having skin-to-skin cuddles with your baby when appropriate.
- When you feel ready and able to, you follow and complete the 'Steps to Home' booklet during your neonatal journey in preparation for discharge home. You can start this from admission and should help you be more involved in your baby's care.
- To bring in supplies for your baby such as nappies, nappy bags, cotton wool, and cotton buds.
- Follow our unit guidelines and policies throughout your stay, such as visiting and infection prevention measures (you will find more information about this in this welcome guide).

Key telephone numbers

Main hospital switchboard:	**01273 696955**
Trevor Mann Baby Unit reception:	**01273 523450/ 01237 696955 Ext. 64377**
Nursery three direct phone:	**01273 696995 Ext. 63948**
Princess Royal Special Care Baby Unit:	**01444 448733**
Outpatient appointments:	**01273 696955 Ext. 64195/64188**

Nursing handover times

Morning	**07:30 - 08:00hrs**
Evening	**19:30 - 20:00hrs**

Please try to avoid calling during handover times as we may be unable to answer promptly. Feel free to ring at any time during the day or night for updates and reassurance.

Medical ward rounds **09:30 - 11:30hrs**

If possible, we encourage you to be present during this time. During ward rounds the medical team will be discussing your baby's care and treatment plans.

If you are in Nursery 1, there will usually be quite a few people around at ward round discussing your baby's care and they may include: the consultant; a registrar (senior doctor); an advanced neonatal nurse practitioner [ANNP]; a senior house officer (junior doctor); and the nurse looking after your baby for the day.

The consultant who is in charge of the medical team will change throughout your stay on TMBU depending on the week and what nursery you are in.

Please ask one of our team members about our family-led ward rounds. These ward rounds may also include other multidisciplinary staff, for example a Speech and Language Therapist [SALT] and a Physiotherapist. These ward rounds aim to empower you as parents so that you are fully aware of what is going on with your baby. It will also be a great opportunity to have all your questions answered, especially questions about your baby's development. If a family-led ward round is something you are interested in, the nursing team can show you how to participate using the prompt sheet.

The nurseries

TMBU is divided into three areas: Intensive Care (Nursery 1), High Dependency (Nursery 2) and Special Care (Nursery 3). We also have a Special Care Baby Unit [SCBU] at Princess Royal Hospital. We are also under one NHS Trust with Worthing and Chichester, although these neonatal units run separately to TMBU and SCBU.

In order to care for your baby, we have lots of specialist equipment and the use of these will depend on the need of your baby. The neonatal staff will go through the equipment your baby is using but if you have any further questions then please do not hesitate to ask us.

As your baby grows and/or progresses they will require less medical support, and this will be reflected in their transition through the nurseries and towards home. Each nursery has its own named consultant for the week and the medical team working specifically in that room.

All staff do move between the nurseries and some staff work between TMBU and SCBU. You can find the named medical staff and nurse in charge of the nursery each day on the whiteboard opposite Nursery 1.

Infection prevention

As a NICU, infection prevention is very important for your baby's well-being because they are at a higher risk of infection. This is why we ask you to wash your hands thoroughly at the sink every time you enter and leave the nursery. In the appendix of this booklet, you will find the World Health Organisation hand washing technique. If you would like your nurse to demonstrate or assess your hand washing, then please ask.

We also ask you to be 'bare below the elbow', which means that you roll up your sleeves (if they are long) and remove all jewellery (unless you have a plain wedding ring, as they do not have to be removed). Please remember to keep your valuables with you at all times.

These infection prevention measures are also expected from any visitors you may have during your baby's stay. Visitors are not allowed to touch or hold your baby because of the risk of infection.

Alcohol gel is provided at every bed space so that you can gel your hands before and after you touch your baby or anything that is inside their incubator or cot.

Your phone can be kept within a wipeable case while you are in the nursery (these are given on admission). We ask that you

do not answer phone calls or video calls in the nursery due to noise levels, so if you need to take one then please do so either in the parent's area or out of the neonatal unit.

Anyone who is feeling unwell should speak with one of our team members, so that we can discuss with you if it is suitable to see your baby at that time.

Visiting

You can be with your baby whenever you wish, day or night. Visiting is restricted to three people at a time, one of which must be a parent/support person. Please check with the nurse looking after your baby about visiting times/restrictions.

Children under the age of 16 years are not allowed to visit (unless they are a sibling of your baby). Due to infection prevention purposes, we ask that only parents/support person and siblings touch your baby whilst they are in our unit.

A support person is someone who you have chosen in place of the other parent, for example if they are no longer involved in yours or your baby's life. Your support person must be the same person for the duration of your baby's stay on the unit.

Only parents/support person are allowed to be present during ward rounds and this is to respect the need for confidentiality and the privacy of each family. However, in the event of an emergency you may be asked to wait outside of the nursery, and we ask that you be patient and understanding with us during these times. We may ask some or all visitors to leave when we have to perform any emergency procedures, or if the number of visitors make it difficult for staff to attend to your baby's needs.

The unit is very warm, so we advise you and your visitors to wear light clothing or layers. Please leave coats and bags in the coat-hanging area, which is just opposite Nursery 2.

Please try to not bring in any valuables onto the unit that will be left unattended. If you need them there are small lockers available in the parent's area for your use, please ask the receptionist for more information.

Quiet time

Quiet time is daily from 3pm-5pm. Only parents/support persons are allowed to visit at this time, so no other visitors should be on the unit.

Quiet time is allocated to help your baby rest and grow whilst they are on the unit. During this time, we try to keep noise and light levels down to help with your baby's ongoing development. We also try to minimise the amount of invasive procedures or investigations being carried out. However, emergency care or procedures will continue at the medics' discretion.

Quiet time is a fantastic time to come and do skin-to-skin cuddles (otherwise known as Kangaroo Care), although we do encourage you do to these cuddles at any time of the day or night if it suits your baby better. If this is not possible because your baby is too unwell, then you can help your baby by doing 'comfort holding' and/or reading to your baby. These will be later discussed in the developmental care section.

Unit facilities

The parents' area is somewhere where you can step away from the nursery and make yourself a cup of tea or coffee and have something to eat. There is a selection of refreshments that are provided by the Early Birth Association and other charities, so please help yourself.

There is a fridge and microwave in the kitchenette, please label any food clearly with your name before placing in the fridge or cupboard. You will find that there are two microwaves, one designated to heating food and one for sterilising equipment such as bottles and breast/chest pump kits.

You will also find a toilet with showering facilities and an expressing room (room 2) in this area. We encourage you to express at your baby's cot side, however this room is provided to make you feel comfortable if you would like more privacy.

You may have noticed that we have two other rooms available in the parents' area. These rooms are available for emergency purposes for parents (for example, if a baby is very unwell and has been admitted from another hospital in the middle of the night).

They are also used if your baby has stayed with us for a while and your baby is nearly ready to go home. If your baby is at that stage, you can stay in one of these rooms with your baby with the support of the special care team from Nursery 3. This is usually for one or two nights and is aimed to ease the transition from hospital to home.

These rooms may also be available for you to use for the day if you are establishing breast/chest feeding, but this will depend on whether the rooms are available, what stage your baby is at in terms of oral feeds and the level of monitoring that is required for them. Please discuss this option with your baby's nurse at the appropriate time.

Confidentiality

To ensure confidentiality, we are unable to give any information about your baby to your visitors and they must be accompanied by you at all times whilst on the neonatal unit. Information regarding your baby will also not be given to relatives over the telephone.

We ask you not to look at, approach, or ask questions about other babies on the unit (unless talking directly to their parents) to respect their privacy.

We also ask that when taking photographs of your baby to please be careful to not include other patients or visitors in them.

As with ward rounds, we urge you to appreciate and respect the need for confidentiality and privacy of each family on the neonatal unit.

Safeguarding children

The Trust has a legal duty to promote the wellbeing and protect the welfare of all children and young people within their care.

It is routine for us to ask about your home environment within the first five days of admission, as this helps us make sure your home environment is safe for your baby when they are ready to go home. We may be able to provide a consultant letter for housing concerns depending on your situation.

We also contact Children's Services once a baby has been an inpatient with us for 90 days. This referral is discussed with you before it is made and is there to help support you when going home, as babies who have been with us for longer than 90 days are likely to require further support in the community.

At times we may feel it necessary to contact our named safeguarding nurse for a baby or family under our care, and if we feel it necessary to refer to social services, we will communicate that with you in a supportive manner.

Consent

While on the unit your baby is likely to have investigations, treatments and procedures that are seen as routine in the neonatal journey. Staff will always try to inform you of any routine blood tests or procedures that are due to be carried out for your baby.

There are some procedures that require consent, either verbal or written, before being completed and these will be discussed with you by either a doctor or nurse if required. Consent must be given by the person with legal 'parental responsibility'.

Car parking

You are entitled to a free parking permit to be used in the Trust car park for up to two car registrations throughout your stay. You will be given a form to complete and this must be taken to the parking office in order to receive your permit/s. Please ask a member of staff if you haven't received a form.

In the appendix you will find a map of the hospital site, the parking office is currently situated in Sussex House on Abbey Road. Please be aware that there are flights of stairs to access the office.

The car park and parking around the hospital can be very busy and difficult at certain times of the day, we suggest you allow extra time to find a parking space. Later in this booklet, you will find information of other forms of transport for visiting your baby if required.

Safety and security

The safety of our patients and staff is paramount and therefore the doors into the neonatal unit are locked at all times. Please use the intercom and state the name of your baby.

Please do not be offended if you have been on the unit for some time and we are asking you to identify yourself still, as this is part of our policy. We ask that you be patient with us at busy times or when a receptionist is not available as it may take longer for staff to answer the bell.

Please do not tailgate into the unit and challenge those who try to. Please inform a member of staff if someone has tailgated onto the unit, or you believe is behaving strangely.

We have a zero tolerance for abuse, discrimination and assault on our members of staff and volunteers. Unacceptable behaviour will not be tolerated, and you will be asked to leave the unit.

Smoking

The Trust operates a no smoking policy. This applies to all patients, visitors and staff. The hospital building and grounds are designated 'NO SMOKING' and we ask for you to please respect this policy. If you do smoke, then you will have to do this off the hospital grounds.

Family integrated care

Our aim is to work in partnership with you as parents to create a consistent and nurturing environment where you feel educated and empowered to be the primary caregivers of your baby.

We believe that you will know your baby best and we want to work with you to show you how you can care for your baby while they are on the neonatal unit. This is a care delivery model known as 'family integrated care'. It has been shown to improve parental experience, parental mental health, breast/chest feeding rates, infant weight gain and parent-infant bonding.

The levels of activity and tasks you can do will depend on how premature your baby is and/or if they are acutely unwell. You can follow the different 'skills' you can learn how to do in your Steps to Home booklet. The unit app will go through neonatal care in detail and what you can do for your baby as the primary caregiver on the neonatal unit. In addition to the app, we also offer:

- Videos you can watch that will show you how to do some of the main tasks for your baby
- Group sessions with other parents
- Bedside teaching

Your baby will benefit from you being present with them for most of the day, but we would like to emphasise the importance of the quality of time rather than the quantity.

We understand that you may have other time commitments and staying on the neonatal unit for most of the day may not be possible for you and your family. We encourage you to find a routine that works well and is sustainable for you, as you and your baby may be with us for a few months depending on the needs of your baby. Please remember to look after yourself and talk with our neonatal staff if you are struggling.

Developmental care

Developmental care refers to the way we watch each baby, learn where they are on their developmental pathway and see what they like and do not like so that we can adapt the way we handle them.

All babies communicate with us through their behaviours. As you gaze at your baby you begin to see the small changes and cues that they are showing you, so spending time to watch your baby will help you in understanding what your baby is telling you. A useful document by Bliss is called "Look at me - I'm talking to you", which goes through this in more detail. It can be accessed for free on their website under 'parent resources'.

Touch is one of the first senses to develop in your baby. Light, feathery touch can sometimes be irritating to your baby, especially if they are under 34 weeks of gestational age. Gentle firm touch

where you hold your hand in one place on your baby's body and one on their head, is more soothing. This is known as 'comfort/ containment holding' and is a great way of letting your baby know you are there.

It is recommended to do some comfort holding on your baby around the time of handling, for example before and after you change their nappy. This is so they can prepare for handling and then settle back down afterwards. Before you do comfort holding, please remember to warm and clean your hands before touching your baby. If you use alcohol gel to clean your hands then please wait a few seconds for the strong smell to disappear.

We follow cue-based care, which is easy to follow as a 'traffic light system'. This means following the signs your baby is giving you so you can see whether they are managing or if they need help to settle. More information on this and development care in general can be found on the unit app, and in your Steps to Home booklet.

Kangaroo care

When your baby is ready, skin-to-skin cuddles (otherwise known as Kangaroo Care) is one of the best forms of touch for you and your baby. It is when you have your baby just in their nappy and on your bare chest and that is why it is called 'skin-to-skin'.

Skin-to-skin cuddles help your baby regulate their own heart rate, breathing rate and temperature, whilst also providing a great bonding experience for you both.

It can also help increase breast/chest milk supply and the bonding experience helps to promote more exclusive breast/chest feeding when it is safe for your baby to do so.

We encourage babies to have skin-to-skin cuddles as much as possible, however this must be balanced with the calories your baby uses to come out of their incubator or cot. As a general rule, we say this to be a minimum of one hour for skin-to-skin, but we encourage longer durations if both you and your baby are comfortable.

Making sure you have eaten, gone to the loo, have water available, are sat in a reclining chair and have a book to read to your baby is a great way to stay as comfortable as possible during Kangaroo Care.

Physiotherapy

The unit has a named physiotherapist who visits the unit regularly to provide support, assessment and teaching for babies and their family. They cover a wide range of topics from respiratory conditions to developmental care and positioning. They are also able to suggest sensory and movement plans after an assessment. They will be present on the multidisciplinary, family-led ward round for advice.

Feeding your baby

If your baby was born early, the main way to get milk into their stomach will be through either a nasogastric tube (NGT) or orogastric tube (OGT). This may also be the case if your baby was born term and unwell, as they will be unable to handle oral feeds (through their mouth) whilst they are poorly.

This tube either goes in through the nose (NGT) or the mouth (OGT) and straight into their stomach. To feed them this way, we need to test the tube every time before we put something through it to make sure the tube is still in their stomach. We do this by doing a pH test. The nurses will show you how to do this so that you are able to get involved with your baby's feeding.

The best milk for a baby is their parent's own breast/chest milk, as it contains important nutrients specifically for your baby that encourages growth and helps to fight infection. We will help support you with expressing and breast/chest feeding if this is something you wish to do.

For preterm babies in particular, breast/chest milk helps protect their gut and this in turn helps protect them from a complication known as necrotising enterocolitis [NEC].

The unit has an expressing room in the parent's area where you will find sterile bottles and expressing pumps. We encourage you to express at the bedside so that you can see and touch your baby, but you are welcome to use the expressing room if this is more comfortable for you. Privacy screens are available to use around your baby's cot space, please ask a nurse to show you where these are stored.

Breast/chest milk is also recommended for mouth care as this can help with the good bacteria in their mouth, but you can use sterile water if there is no breast/chest milk available.

Donor milk can also be used in the absence of your own milk, with your consent. For preterm babies, we will need to use donor milk rather than formula in the early weeks due to their fragile gut. We use a donor milk bank where strict guidelines are followed in the testing and pasteurising of the milk. Please see the leaflet on donor milk for more information on this process.

If formula is introduced for preterm babies, we will need to do this slowly and gradually so that we can watch how your baby is tolerating these feeds. We have a special preterm formula for this purpose and if your baby is on a preterm formula, they will most likely go home on a follow-on specialist formula. If this is the case, we will give you a prescription form to give to your GP so that you are able to obtain it on discharge.

When your baby is ready for oral feeds, we may start slowly as it can tire your baby out easily as they try to figure out what to do. If your baby was born early, it is usually around 34 weeks that their sucking, swallowing and breathing reflexes develop and coordinate, but this may vary from baby to baby.

Using a dummy can help strengthen the muscles in their jaw, this can be offered during tube feeds and is known as non-nutritive sucking. When suitable, we can start completing 'dummy dips' with milk. By doing this baby gets to taste the milk and practice their sucking and swallowing skills.

If you wish to breast/chest feed, we may put your baby to an empty or partially full breast/chest at first. If you wish to bottle feed, then we may start off with just a small amount of milk in the bottle and position your baby on their side to help them pace themselves.

We may involve Speech and Language Therapists to assess your baby and their sucking ability in order to make sure your baby is feeding safely.

If you need help or advice with breast/chest feeding or bottle feeding, then just ask your nurse to help you. We also have an infant feeding specialist available, so if you feel as though you would like some extra support then please just let us know.

More information on 'feeding my baby' can be found on the unit app.

Speech and language therapist [SALT]

We have a team of specialists who visit the unit regularly to provide support and advice when establishing feeding. Whether this is by breast/chest or bottle, they assess your baby's suck and swallow reflexes and will most likely start this process well before your baby is introduced to oral feeds.

They are able to give you strategies to prepare your baby for oral feeds with sucking practice or tolerance of touch around the mouth. Not all babies will require this service and is assessed by patient needs, so if it is felt as though this service would be helpful for your baby then we will let you know. If you would like to know more about this service, then please speak to the nurse or doctor looking after your baby.

Ophthalmology

All babies born more than 8 weeks early or weighing less than 1.5kg will receive regular eye examinations by one of our ophthalmologists (eye specialist). They come to the neonatal unit and screen the babies at the cot side.

The first examination will be done when your baby is between 4 and 6 weeks old. Some babies will need only one examination, although most babies need at least two.

They are screening for retinopathy of prematurity [ROP]. The ophthalmologist will look specifically at the retina (a part at the back of the eye sensitive to light) to check for signs of ROP. There is an information leaflet for parents on ROP. Please ask your nurse for a copy of this to find out more.

On the day of the examination (usually a Wednesday) the nurse looking after your baby will administer eye drops in the hour leading up to the examination. This is to dilate the pupil so that the retina can be seen.

The examination can be uncomfortable, and babies may show signs of distress. Containment holding and breast/chest milk or sucrose (sugar solution) can be used to help calm them. The ophthalmologist will make the procedure as quick as possible, although it is important that they have enough time to see the retina properly.

At times a camera may be used to take photos of the retina, and a speculum may be used to keep the eyelid open during the examination. Local anaesthetic eye drops will be used to minimise discomfort to your baby.

The neonatal transfer service

The neonatal transfer service for Sussex is based on TMBU and have a specialised transport ambulance just for neonatal transfers. They work alongside other transfer teams in Kent and Surrey to cover the neonatal network in this region and the three teams rotate to cover the transport service 24/7.

As a service, it means that babies can be moved where they need to be, whether that be because of an emergency to come to a unit like ours or to be moved safely back to the booking hospital or another hospital that is closer to home (sometimes you may hear the term repatriated).

The team consists of a doctor/advanced neonatal nurse practitioner and a senior nurse experienced in neonatal transport.

If your baby was born in another hospital then you may have already used this service, or it may be that your baby was born here because it was safe to move you/your partner before the birth. If you did not book to have your baby at our hospital, we aim to move your baby back to a hospital closer to home through the transport team when it is appropriate to do so.

Sometimes it is appropriate to move your baby back to a hospital closer to home very quickly, and in other situations it may be months. This is dependent on the need of your baby and the service that can be provided at the neonatal unit (or sometimes paediatric ward) closer to your home. If we feel as though your baby is almost ready to be moved, then we will discuss this with you at that time.

Preparation for home

We have a dedicated special care team who you will meet when your baby moves into Nursery 3. The team is there to help prepare you and your baby to go home.

The steps that need to take place in order for your baby to be discharged are outlined in the 'train to discharge' page in your My Journey booklet and are also discussed in the Steps to Home booklet. You can start these booklets from admission as they go through what you can do depending on the stage your baby is at.

In terms of discharge, the basic steps your baby needs to take include:

- they can maintain their own temperature in a non-heated cot
- they no longer require any monitoring
- they can feed safely
- they are putting on weight.

The special care team will go through with you any advice for getting your baby home safely, as well as discussing with you what you will need at home.

They ask that you attend the infant basic life support before your baby is discharged and they will arrange this for you at a suitable time. The team also work alongside the neonatal outreach team to help with the transition from being in hospital to going home.

The neonatal outreach team

The neonatal outreach team consists of two neonatal nurses. You will meet these team members when your baby has moved into Nursery 3.

As a service they offer a continuation of care between TMBU/SCBU and home. They work alongside your health visitor to help smooth the transition of being at home with your baby. You will meet the team before your baby is discharged and they will discuss with you your baby's needs and how they can support you.

Some of the things they can help with include:

- Feeding support
- Arrange discharge planning meetings (if appropriate)
- Carry out referrals (e.g., dietician, mental health support)
- Work with other community team members (e.g., GP, HV, stoma nurses, community nurses)
- Support you and your baby if they need to go home on oxygen
- Carry out blood tests at home.

It is a short-term service so eventually the care of supporting you and your baby at home will be with your health visitor alongside other community support.

If your baby is discharged home on oxygen or they have other care needs, then they will be referred to the Children's Community Nursing Team for continued medical care and support.

Financial support

We understand that having a baby in hospital can be a cause of unforeseen financial strain and stress. Unfortunately, there is currently no national support fund for families receiving neonatal care.

If you are experiencing financial hardship please do not suffer in silence, talk to a member of staff who may be able to help you find solutions. You can contact your local Jobcentre Plus office and/or apply for a social fund. There is also a wealth of advice on financial support on the Bliss charity website under Financial Information.

Charities and other support available

For many, the journey through a neonatal unit can be overwhelming and stressful. The unit staff are always here to support you and answer any questions you and your family may have.

The following list of charities can provide further support and information on various topics. Some of the charities also have parent groups and networks that can connect you with others who have gone through similar experiences to yourself.

We have found that some families contact other support networks from early on, while others contact them later in their journey when things have settled. Others wait until they have gone home and are looking back on their experiences and find that they would like further support. Each family is different, and the support is there no matter where you are in your journey.

- **The Early Birth Association [EBA]** - The EBA is a local charity who were created to make a positive difference for babies and families and the teams who work on the units by providing a wide variety of help and support. This ranges from providing practical items for the babies and parents on the units to make their hospital stay more homely and comfortable, to funding vital lifesaving equipment and research. The EBA is run by a group of volunteer parents and family members who have had premature or sick babies. They offer help and support, both emotional and practical, to parents who are facing the same worrying experiences that they once faced by regularly visiting the unit to run informal drop in coffee mornings, and by ensuring the units are stocked up with items and equipment that they need. **www.earlybirth.co.uk**
- **Bliss -** Bliss is the leading UK charity for premature and sick babies. They support parents with both practical help and emotional support. They have published many informative leaflets, have dedicated face to face volunteers who visit the unit to provide support, as well as an email service to provide support for those who would prefer this type of support. They are also heavily involved in improving standards of practice and care of the premature and sick infant by working alongside healthcare professionals to provide training, support and research. Furthermore, the charity campaigns and lobbies for changes to policy, investment and standards of care in order to make a lasting difference to neonatal services right across the UK. Bliss aims to standardise the care received by a family no matter where in the country you and your baby are cared for. **www.bliss.org.uk**

- **Mothers Union** - The Mothers' Union are an international community-based christian volunteer movement with a local branch based in Brighton. They work with families of all faiths and none and visit the unit regularly to provide a listening and supportive ear to parents, while providing delicious baked goods.
- **Amaze (Brighton support group)** - Amaze are a charity that provide advice and support to families of children and young people with special educational needs in Brighton & Hove and Sussex. **Advice Line: 01273 772289 www.amazesussex.org.uk**
- **Contact** - A charity for families with disabled children. They provide information, advice and support, as well as workshops for families. You can talk to an adviser through their helpline, access emotional support through their 'listening Ear' service or connect with online communities. They also campaign for policy change and research to tackle inequalities faced by families with disabled children. **Helpline: 0808 808 3555** (Monday-Friday, 9:30am-5.00pm) **www.contact.org.uk**
- **Group B Strep Support** - This UK wide charity provides information and support to families affected by Group B Strep (GBS). They raise awareness and provide education to aid in preventing and spotting early warning signs. As well as campaigning for changes to policy and research into GBS. Their helpline is open to provide you with support and answers to your questions around GBS. **Helpline: 0330 120 0796** (Monday-Friday, 9am - 5pm) **www.gbss.org.uk**
- **Twins Trust** - Formally known as TAMBA [Twins and multiple Birth Association], this charity provides support and information to families of multiple births. Twinline is their support line for parents wishing to speak with other

multiple birth parents for support, reassurance or guidance. **Twinline:** 0800 138 0509 (Monday to Friday, 10.00am-1.00pm and again at 7.00pm-10.00pm) www.twinstrust.org

- **NEC UK** - A parent led organisation that offers support to families affected by the condition at any stage of their infants' journey. They offer support groups via online platforms and through emails, where families can share their experiences and coping strategies. You can email them on info@necuk.org.uk or visit their website www.necuk.org.uk
- **TOFS [Tracheo-Oesophageal Fistula Support]** - A charity dedicated to improving lives for those born with OA/TOF/ VACTERL conditions. They do so by offering one-to-one support, a range of information and resources for families. They can be contact via telephone: 01159 613092 or via email: info@tofs.org.uk
- **NCT [National Childbirth Trust]** - The NCT's mission is to support parents through the first 1,000 days to have the best possible experience of pregnancy, birth and early parenthood. They have lots of advice and support on their website for new parents. Their helpline provides practical and emotional support with feeding your baby as well as general information. Please see their website for usual opening hours. **Helpline:** 0300 330 0700, www.nct.org.uk
- **Sands** - Sands is the leading stillbirth and neonatal death charity in the UK. They provide support for anyone affected by the death of a baby for as long as they need it. They provide bereavement support via their helpline, online community and resources, and a mobile app. **Helpline:** 0808 164 3332 www.sands.org.uk

Counselling service

We understand that having a premature and/or sick baby can be extremely scary and stressful for both parents and the wider family.

We can offer support through our counsellor who would be happy to meet you either on the unit, or if you would prefer away from the unit. This can be arranged for a mutually convenient time. Please speak to a member of staff if you would like more information regarding this service.

Spiritual wellbeing

Whether you have a faith, or identify with none, the chaplaincy team is available to all on the unit at any time to provide spiritual support or just lend a listening ear.

The team are also able to contact the various local religious leaders appropriate to your faith tradition if you would prefer. Please speak to your nurse about your spiritual needs or contact the chaplaincy team on **01273 696955 Ext. 64122.**

You may wish to have your baby baptised and blessed or have another religious ceremony while on the unit. Please speak to the nurse looking after your baby, or the chaplaincy team if you would like to arrange this.

vCreate

vCreate is an NHS Trusted Secure Video Messaging service that enables the team to send you short videos and photos of your baby, during those times when you are unable to be on the unit. The photos and video clips will be general updates only and will not contain sensitive or clinical information. The clips will be taken on a unit-approved device.

You will be asked to register for a vCreate account on the units dedicated vCreate URL, which will then be approved and activated by the unit system administrator. When new content is uploaded you will be notified by email or text.

This photo/video diary builds up over time and is accessible on demand 24/7. You will then be able to download the content to a computer upon discharge.

If you are transferred to another hospital the account can also be transferred if the receiving unit uses the same system. Once you have been discharged the system administrator will permanently remove the videos and associated data record.

To register for an account please go to: **www.vcreate.tv/unit/247.** You will also be required to sign a consent form on the unit prior to the account being activated.

Feedback and complaints

Feedback: We would be grateful to receive your views on any aspect of our services. The information you give helps us to identify areas where we are doing well and where we need to make improvements. There are feedback cards and a locked box located in the family area which can be filled out whenever and as often as you like during your stay. These can be completed by yourselves or your visitors, please use these for suggestions of improvements or indeed to highlight something positive. When you are getting ready to be discharged, we will ask you to complete a questionnaire on one of the unit's iPads, we really do appreciate all the feedback that we receive. Once you are discharged home you will receive a text message from the trust asking for feedback. This is generated by the hospital rather than the unit but is still valuable feedback. All feedback is completely confidential.

Complaints: If you have any concerns or complaints regarding the unit, nursing or medical staff, or any other issue, please let a member of staff know immediately. Often, we are able to resolve any issues promptly and directly. You may feel more comfortable speaking with the nurse in charge, the sister on management, or the matron. This can be arranged easily so please ask a member of staff to notify the relevant staff member to arrange a mutually convenient time. If you would prefer to speak to someone outside of the unit then the Patient Advice and Liaison Service (PALS) is available to discuss any areas of concern you may have while your baby is on the unit. You can either ask the unit staff to contact them for you or contact them directly by telephone. Please see the latest PALS leaflet available on the leaflets and information stand or online on the trust website. Contact details to write to the chief executive are also included in the *How to Make a Complaint* leaflet.

The local area

Time spent at the hospital can be very exhausting in a lot of different ways, which is why it is important to take breaks for your well-being. It can also be very daunting if you are staying away from home and are not familiar with the surrounding area. We hope that this area information will help you feel more comfortable with staying near the hospital.

The Royal Sussex County Hospital is situated in the Kemp Town area of Brighton and Hove. There is a selection of coffee shops, cafe's, pubs and some small local shops including a Co-Op. You can find many of these establishments on St. George's Road (between the hospital and the seafront).

Nearby you will also find Brighton Marina (about a 20-minute walk from the hospital), which has a large Asda superstore, numerous restaurants and some entertainment facilities, such as a cinema and bowling. The Marina will also give you access to the under-cliff walk where you can walk/cycle/run along the seafront to Saltdean. There is free parking available at the Marina for up to 4 hours.

Along the seafront in Kemp Town, you will find beach bars and coffee shops, some outdoor exercise establishments and some more entertainment facilities. You can continue to walk/cycle/run along this seafront road past the Palace Pier and continue up to Hove Lagoon as part of the 'local health walk'.

It is around the Palace Pier where the city centre begins and where you can find all the local shops, cafe's and coffee shops that Brighton and Hove is well-known for. There is also Churchill Square shopping centre (near the i360) where you can find the majority of the popular high street stores.

For any transportation needs, Brighton and Hove buses are one of the best methods for getting around the city. Around the hospital, the buses 1/1A, 7 and 23 are the ones that stop just outside the main entrance. You can download the free Brighton and Hove bus app for all routes, timetables and fares (it is recommended to buy your ticket via the app).

The closest train station is Brighton, but it is approximately a 35 minute walk to the hospital, or you can get one of the buses from outside the station.

If you require a taxi, there are a selection of local taxi companies which can be contacted on: **01273 204060, 01273 202020 or 01273 205205.**

Frequently asked questions

"How long will my baby be in neonatal care for?"

This is not a simple question to answer as it will completely depend on the need of your baby, but as an estimate for preterm babies:

- 24 weeks and under - four to five months
- 25 weeks - around four months
- 26 weeks - three to four months
- 27 weeks - around three months
- 28 weeks - two to three months
- 29 weeks - one to two months
- 30 weeks - a little over a month
- 31 weeks - around a month

For your baby to go home, they will need to reach a few different milestones. These include: if your baby can maintain their own

temperature in a non-heated cot; they have at least the majority of their feeds orally; they have been putting on weight well; and if their observations have been stable with either no oxygen or the amount of oxygen they have been assessed as safe to go home with.

Some babies (particularly if they were born very early) may need to be moved to the Royal Alexandra Children's Hospital [RACH], or another paediatric hospital/ward that is closer to your home. This may be the case if your baby is still needing ongoing respiratory support and/or surgical input around the time of their due date. Although it is a big change to move to a paediatric ward compared with a neonatal unit, the paediatric teams have excellent specialist input to help suit your baby's needs as they continue to grow, and it is therefore the best place for your baby. If this is the case, we try to arrange for you to view the ward at RACH and meet the team before your baby is transferred.

If your baby was born term and unwell and/or needed surgical input, then again this will vary on the needs of your baby. Some babies only need to stay with us for a few days and others a few weeks. It is best to discuss this with the nurses and doctors who are looking after your baby once your baby is starting to recover.

"Is there parent accommodation available?"

As far as possible we try to accommodate parents who do not live locally in the nearby Ronald McDonald House on Abbey Road or in the Royal Alexander Children's Hospital. This accommodation is free (a deposit is required and returnable when leaving) but it is limited, so there may be a waiting list at times. The house on Abbey Road has eight en-suite bedrooms, lounge, dining area, kitchen, laundry facilities and a small patio garden. The Ronald

McDonald House also offers 'day passes' for parents who are not staying with them but have need for time away from the unit. There they can use the living room and laundry facilities, as well as take a bath or cook themselves a meal. Please ask your nurse for more details on this.

On the unit we have two comfortably furnished bedrooms with toilet facilities for parents to use mainly when establishing feedings and for a few nights prior to discharge home with their baby (rooming in). These rooms function as a half-way house with support from neonatal staff readily available. In addition, the expressing room can also be turned in to a third bedroom if required.

"What should I bring in for my baby?"

We supply most things for your baby, but we ask you to bring in nappies, nappy bags, cotton wool and cotton buds. When suitable for your baby you can bring in clothes to change them into, although we also have lots of clothes available on the unit, but we understand that you may wish to dress them in clothes you have bought. You can also bring in muslins and blankets if you wish. We ask that if you bring in any clothing items to please wash them at a high heat of 60 degrees. We can provide bags to put your baby's dirty laundry in, but we would advise you to put your baby's name on any clothing items in case they accidentally get put in our laundry system.

You may wish to bring in a toy for your baby, but we ask you to only put it in your baby's cot when they are in an open cot. We also ask you to only keep one in the cot at a time for infection prevention purposes. If your baby is in an incubator, then you can still bring a toy in, but it will have to be put on top of the

incubator or be kept in the drawer in the meantime. In terms of development, some toys can represent heartbeat sounds which can be soothing to your baby. If your baby is closer to term age, they may also enjoy some musical ones, ones with lights, mobiles, bouncy chairs etc. These are beneficial for your baby's development, but it is important to use these when your baby is awake so that it is not over-stimulating for them. This is also the case with black and white images, please only use them during awake periods and do not leave the images in your baby's cot as sometimes they are unable to break the gaze. There are lots of books available on the unit for you to read to your baby, but you may wish to bring your own books in. If you are unsure what to bring in for your baby's developmental needs, then please either speak with the Therapy Team (physiotherapist/SALT) or the nurse looking after your baby.

You may also wish to make mementos from your baby's neonatal journey. We collect items such as monitoring leads and umbilical clips that are no longer required and place them in a memory bag attached to your baby's incubator/cot. These are for you to take and keep if you wish. You may also like to take hand and footprints, either with ink or clay. Please speak to a member of staff to arrange the best time to do these, we take in to account baby's condition and progress. For example, clay prints can be tricky to complete with small, more fragile babies.

"Where can I hire an expressing pump?"

We provide expressing pumps for use whilst you are visiting your baby on the neonatal unit. Each family will be given a pumping set that includes a cooler bag to transport your milk to the hospital, all of which you may keep after your baby is discharged from our care. We use Medela expressing pumps, so only this brand of machines will be compatible with the pumping sets we hand out. We are unable to hire out our unit expressing pumps but there are outside companies available. The information on these companies can be found in the expressing room or you can ask one of the nursing team for more information. However, it can be quite costly if you're needing to express at home for a long period of time, in which case you may wish to purchase your own.

"Will my baby need follow-up care?"

Many babies born early will reach their developmental milestones according to how early they were born. For instance, a baby born two months early may start to sit up at eight months rather than six months.

Although all babies develop at slightly different rates, most premature babies will catch up with other children by the time they are about two years old. Unfortunately, babies born very early are at an increased risk of developmental delay. We carefully monitor developmental progress in all babies, but particularly those born before 33 weeks. This is so we can identify any potential delays and refer onto other specialists, such as physiotherapy or SALT, if required.

If your baby requires follow-up care, then this will be discussed with you before your baby is discharged.

"Do I need to let my GP or Health Visitor know if my baby has been born?"

When a baby if first born, the midwifery team will notify your GP and we will contact the Health Visiting team in your area. However, you will need to register your baby with your GP before your baby is discharged from hospital. When your baby is in hospital, your Health Visitor may call us and you and/o visit you at home to see how you are and how your baby is progressing. Once your baby is discharged, we will notify both your Health Visitor and GP.

"Where can I register my baby's birth?"

You will need to register your baby's birth within six weeks, and within the area your baby was born. If you are unable to register the birth in the area they were born due to being transferred to another hospital, you can go to another registry office who can send your details to the correct office. When contacting the registry office please make them aware that your baby was born out of area. If you are married, either parent can register the birth. If you are not married and want the baby to be registered in the father's name, both parents must attend. The following are the local county offices details, you can book an appointment online or over the phone. If your baby was born at Brighton, you can register the birth at either Brighton or Lewes office.

Brighton and Hove Register Office

Brighton Town Hall

Bartholomew's Square, Brighton, BN1 1JA

01273 292016

Eastbourne Register Office

Town Hall

Grove Road, Eastbourne, East Sussex, BN21 4UG

01323 464780

Hastings Register Office

The register Office

Summerfields, Bohemia Road, Hastings, TN34 1EX

01424 726530

Haywards Heath Register Office

County Offices

Oaklands, Oaklands Road, Haywards Heath, West Sussex, RH16 1SU

01243 642122

Lewes Register Office

Southover Grange

Southover Road, Lewes, East Sussex, BN7 1TP

01273 475589

Worthing Register Office

Portland House,

Richmond Road, Worthing, BN11 1HS

01243 642122

Appendix

- **Weight Conversion Chart**
- **WHO Hand Washing Technique**
- **Words You May Hear on the Unit**
- **Royal Sussex County Hospital Map**
- **Princess Royal Hospital Map**

Weight conversion chart

Converting Your Baby's Weight from Grams to Pounds.

To find your baby's weight in pounds and ounces, locate on the chart their weight in grams. The number along the top will give you pounds and the number to the left side will give you ounces. For example, if your baby weighs 1134 grams, then they weigh 2 pounds and 8 ounces.

	lbs	0	1	2	3	4	5	6	7	8	9	10
oz						Grams						
0		0	454	907	1361	1814	2266	2722	3175	3629	4082	4536
1		28	482	936	1399	1843	2268	2750	3203	3657	4111	4564
2		57	510	964	1471	1871	2325	2788	3232	3695	4139	4593
3		85	539	992	1446	1899	2353	2807	3260	3714	4167	4621
4		113	567	1021	1474	1928	2381	2835	3289	3742	4196	4649
5		142	595	1049	1503	1956	2410	2863	3317	3770	4224	4678
6		170	624	1077	1531	1984	2438	2892	3345	3799	4252	4706
7		198	652	1106	1559	2013	2466	2920	3374	3827	4281	4734
8		227	680	1134	1568	2041	2495	2948	3402	3856	4309	4763
9		255	709	1162	1616	2070	2523	2977	3430	3884	4337	4791
10		283	737	1191	1644	2098	2551	3005	3459	3912	4366	4819
11		312	765	1219	1673	2126	2580	3033	3487	3941	4394	4848
12		340	794	1247	1701	2155	2608	3062	3515	3969	4423	4876
13		369	822	1276	1729	2183	2637	3090	3544	3997	4451	4904
14		397	850	1304	1758	2211	2665	3118	3572	4026	4479	4983
15		425	879	1332	1786	2240	2693	3147	3600	4054	4508	4961

World Health Organization

Patient Safety

A World Alliance for Safer Health Care

SAVE LIVES
Clean **Your** Hands

How to Handwash?

WASH HANDS WHEN VISIBLY SOILED! OTHERWISE, USE HANDRUB

Duration of the entire procedure: 40-60 seconds

0

Wet hands with water;

1

Apply enough soap to cover all hand surfaces;

2

Rub hands palm to palm;

3

Right palm over left dorsum with interlaced fingers and vice versa;

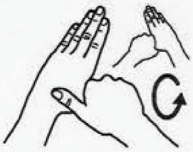
4

Palm to palm with fingers interlaced;

5

Backs of fingers to opposing palms with fingers interlocked;

6

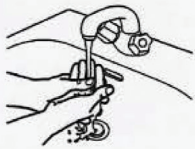


Rotational rubbing of left thumb clasped in right palm and vice versa;

7

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

8

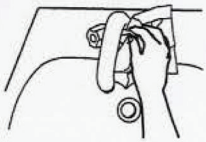


Rinse hands with water;

9

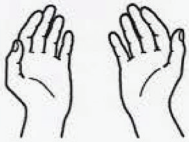
Dry hands thoroughly with a single use towel;

10



Use towel to turn off faucet;

11



Your hands are now safe.

Words you may hear on the unit

A

Anaemia - The name given to a condition when there is too little haemoglobin in the blood. Haemoglobin is found inside red blood cells and carries oxygen around the body.

ANNP - Advanced neonatal Nurse practitioner. A nurse who has completed further training and is able to complete tasks that a doctor can.

Antibiotics - Used to treat suspected or known bacterial infections.

Apgar Score - The score used when baby is first born as a simple way of checking baby's heart rate, breathing, colour and tone.

Apnoea - When there is a pause in breathing for longer than 20 seconds. Premature babies may commonly suffer from this as the part of their brain that controls the respiratory system is not yet fully developed. You may see staff gently stimulating them, and it is likely they will be on caffeine as a stimulator. Most premature infants grow out of this before 36 weeks.

Arterial Line - A plastic tube that might be inserted either into the umbilical cord or in an artery in one of their limbs. This is used to continuously monitor the baby's blood pressure and take blood samples without the need for needles/heel pricks. It is an invasive form of blood pressure monitoring but is needed if their blood pressure has been unstable and they are requiring medicine to support it. Arterial lines may be used for babies requiring surgery and also if an exchange transfusion is needed.

Aspirate - This can be used in two ways when used on the neonatal unit. The first is related to feeding. Before using a feeding tube an

aspirate will be taken to check that the tube is in the same position. A small amount of liquid from the baby's stomach will be 'aspirated' and tested. The second way is used when something other than air has been inhaled into a baby's lungs. For example, they may have inhaled meconium at delivery (meconium aspiration) or inhaled a small amount of milk when feeding orally.

Audiology test - Every baby will be offered hearing screening prior to discharge home. This is done in the last 24 hours before going home. Small earphones are placed over baby's ears and a machine measures the baby's response to sound to detection hearing impairment at the earliest possible age.

B

Bagging - This term is used when describing the need to use a mask attached to a squeezable bag over a baby's nose and mouth to deliver breaths to the baby.

Bilirubin - This refers to a yellow substance produced in your blood when the red blood cells break down at the end of their life cycle. It is usually broken down in the liver and digestive tract before being excreted and is very normal. However, high levels in the blood can be dangerous. The level is referred to as an SBR. It may present in babies as jaundice, where a baby appears yellowish.

Blood cultures - A sample of blood is taken from the vein and sent to the laboratory for testing if infection is suspected. Results will be back after 48 hours.

Blood gas - A small amount of blood is taken and tested on the unit with results available straight away. It looks at how well the baby's respiratory system is coping, as well as looking at baby's electrolytes, blood sugar levels, and whether the baby is anaemic.

Blood pressure - A measurement of the pressure generated by the heart. This can be measured with a cuff around the baby's arm or leg, or through a line into an artery. Babies may need medication if their blood pressure is too low.

Blood transfusion - Administering donor blood through a vein to give the baby extra blood. This may be required when a baby has anaemia, low blood pressure, or when having a procedure carried out such as surgery.

BM - Used when talking about the level of sugar (glucose) in the blood.

Bradycardia - When the heart rate drops to lower than the normal range. The baby usually recovers by themselves, but they may need gentle stimulation at times.

C

Cannula - A small, soft plastic tube that is inserted into a vein and fixed with tape so that medications and fluid can be given to baby without needing to use a needle every time.

Centile - Found on growth charts showing normal ranges.

Cranial ultrasound - Carried out on the unit by a doctor or ANNP, a non-invasive scan to examine the brain. All preterm infants less than 32 weeks as routinely scanned on days 1, 3 and 7, and then again at day 28. Other scans and follow ups may be required, this is at the doctor's request. Infants born greater than 32 weeks may still require scans, these will be discussed and explained by the doctor.

CSF (cerebrospinal fluid) - A clear fluid that surrounds the brain and spinal cord.

CFM (cerebral function monitor) - A machine that monitors brain wave activity through little needle electrodes placed in the scalp.

It is important in assessment and management of babies who are fitting or have an abnormal level of consciousness. It is used when a baby is having cooling treatment.

Chest Drain - A tube that is inserted into the chest wall and sits in the space between the lungs and the outside chest wall. This is used to drain air or fluid that has been leaking and collected in the lung.

Chronic lung disease - A condition of the lung that may occur due to damage to the fragile lung tissue from requiring respiratory support, such as ventilation, for a long period of time.

Cooling - A treatment used for hypoxic ischaemic encephalopathy (HIE) to try to prevent further injury to the brain. The body's core temperature is reduced using a mattress for 72 hours before being slowly rewarmed.

CPAP (Continuous positive airway pressure) - Non-invasive respiratory support. A small amount of pressure produced by air is used to keep the lungs expanded slightly to make it easier for the baby to breath themselves. This is through nasal prongs or a mask over the nose. A premature baby may require CPAP support on and off as they grow and gain strength.

CT - A machine to gain a more detailed X-Ray. The baby will be transported accompanied by their nurse and doctor/ANNP in an incubator to the CT machine on another level of the hospital. Images take a few days to be interpreted by the radiologist.

E

EBM (expressed breast milk) - Mothers milk that has been expressed either by hand or pump, this can be kept in the fridge or freezer until baby is ready to use it.

ECG (electrocardiogram) - Usually three leads placed on a baby's chest to look at the rhythm of the heart, this is routine monitoring within the NICU. Sometimes a 12 lead ECG may be required, a doctor will discuss the reasons for this beforehand.

Echo - This term refers to an echocardiogram. An ultrasound scan of the heart that takes place on the unit, so the baby does not need to be moved. The doctor or ANNP can see the structure of the heart and the blood flow within it to pick up any abnormalities.

EEG (electroencephalogram) - A test used to look at the brain's electrical activity. It is important in assessment and management of babies who are fitting or have an abnormal level of consciousness. This test will be arranged with specialists who will visit the unit so that the baby does not need to be moved.

Electrolytes - The salts and minerals found in blood.

ET Tube - The endotracheal tube is a soft plastic tube that is placed through the mouth or nose into a baby's windpipe to ventilate the baby invasively.

Exchange transfusion - The process where the blood is replaced with donor blood when a baby is suffering from severe jaundice that is not correcting with normal treatment, such as phototherapy.

Extubation - The removal of the ET tube from the baby's windpipe.

G

Grunting - A word used to describe the noise a baby with breathing difficulties makes.

H

HDU (High dependency unit) - Providing support for babies who require less intensive care than those is NICU but are not yet stable enough to be in special care. These babies include those requiring non-invasive respiratory support or TPN.

Heel prick - A small lancet pierces the skin of the heel to obtain a blood sample. This is used when only a small amount of blood is required.

Humidity - Humidity is used to prevent premature babies losing too much water and heat through their skin. For example, babies born under a certain gestation are nursed in humidified incubators. The unit also uses humidity in all their respiratory support, this makes it much more comfortable for the baby.

I

Incubator - A heated bed covered by clear plastic so that the smallest infants can be kept warm without being clothed. This means medical staff can observe the baby closely for any change to their skin or breathing.

Inotrope - Drugs used to help increase blood pressure.

Intubation - The process of inserting an ET tube into the windpipe to take over a baby's breathing.

Intravenous (IV) - Used to describe giving medication or fluids directly into a vein through a cannula.

IVH (Intra-ventricular haemorrhage) - Where there is a bleed into the ventricles (fluid chambers) of the brain. They are graded from 1 to 4 according to their size. Grade 1 bleeds can be quite common in premature babies, these may have no significant long-term consequence for the baby. A grade 4 bleed is the highest grade and may have significant long-term consequences.

J

Jaundice - A yellowing of the skin and/or whites of the eyes due to high levels of bilirubin. It is very common in newborn babies. Doctors measure the level of jaundice and may feel it necessary to treat if levels are high. It is treated with phototherapy, and/or fluid therapy.

L

Long line - A very fine, soft plastic tube inserted into a large vein, with the end lying close to the heart. You may hear them being called a CVL (central venous line). They are inserted under sterile conditions and kept sterile under dressings. Medication and nutrition can be given through them.

Low flow oxygen - Administering small amounts of oxygen usually through nasal cannula.

Lumbar puncture (LP) - A procedure carried out on the unit by a doctor or ANNP. A needle is inserted into the space between the spine to take some spinal fluid for testing. This will be carried out if sepsis is suspected. It may also be used to treat very high pressure in the brain.

M

MRI (Magnetic resonance imaging) - A scan that is completed away from the unit on another level of the hospital. The baby is moved into a transport incubator and accompanied their nurse and a doctor/ANNP. Scan results will often take several days for preliminary results to be available. They may be sent to a specialist for confirmation.

Meconium - The first bowel movements of a newborn, dark green and sticky in appearance.

N

Nasal cannula – A small, soft tubes that rest just inside the nostrils to provide oxygen.

Nasogastric tube (NGT) - A long plastic tube that is passed into the stomach via the nostril. This is then used to give a baby milk and medicine until they are old enough and strong enough to take it orally.

Neopuff - A piece of equipment used by a nurse/doctor/ANNP to deliver breaths to the baby. This may be via a mask or attached directly to an ET tube. This may be required if a baby has an apnoea or when transferring a baby from one bed to another.

NICU (neonatal intensive care unit) - The highest level of care for the sickest babies. This may include babies born extremely premature, those requiring invasive respiratory support, invasive blood pressure monitoring and support, those who have had traumatic deliveries, and babies requiring surgery.

Nitric oxide (inhaled) - A gas that is administered to help relax blood vessels in the lungs for gas exchange. This is used for very sick infants receiving care in an intensive care environment.

O

Oedema - Swelling or puffiness caused by too much fluid being retained under the skin.

Orogastric tube (OGT) - A long plastic tube that is passed into the stomach via the mouth. This is then used to give a baby milk and medicine until they are old enough and strong enough to take it orally.

Oxygen saturations - The measurement taken, usually by a probe on the wrist, hand or foot. It measures the amount of oxygen flowing through the blood in a %. Neonates have specific oxygen saturation ranges depending on their gestational age and condition, please ask your nurse for your baby's specific range.

Optiflow (Humidified High Flow Nasal Cannulae) - A respiratory support device that delivers oxygen non-invasively into the nose via nasal cannula. This is a step down from CPAP support.

Oscillation - An invasive respiratory support used in intensive care to care for very sick infants. It appears that the chest is wobbling or vibrating rather than rising and falling in normal breaths. This can be distressing to see but can be a very effective form of ventilation in specific conditions.

P

PDA (Patent Ductus Arteriosus) - All babies are born with an open duct between the vessels supplying the lungs with blood, and the vessels supplying blood to the body. This should close naturally within hours of birth in a term infant; however it is very common for them to stay open in premature infants. Sometimes they may close on their own, however they may require medication or surgery to close them. A baby will have scans of the heart regularly to check that it is closing.

pH - The acidity or alkalinity of a solution, such as blood or stomach contents. This measurement is used on the unit when testing a feeding tube to check its position, and in blood samples to check that the baby is ventilated correctly.

Phototherapy - A special blue light that enhances the break down and elimination of bilirubin to treat jaundice.

Platelets - A component in the blood that helps with clotting. A baby may receive a transfusion if levels are too low.

Pneumothorax - When air has leaked between the lung and chest wall making it hard for the lung to expand properly when breathing in.

Posset - When a baby brings up a small amount of milk after a feed, the volume is less than enough to define as a vomit.

R

ROP (retinopathy of prematurity) - Where damage has occurred to the back area (retina) of the eye. It is related to the amount of oxygen in the blood reaching the retina. Severe damage if not corrected with surgery can cause the retina to detach and blindness. Preterm infants are regularly screened by the ophthalmologist. Please ask your nurse for more details on the screening process.

S

SALT (Speech and Language Team)

SCBU (special care baby unit) - Babies requiring support in terms of feeding and growing but require less support with their breathing. Special care nurseries are preparing families for discharge home.

Sleep study - A test usually completed in the special care nursery when a baby has been on nasal cannula oxygen for a long time, and it looks likely they will be going home requiring oxygen. The test will show if the baby is able to keep their oxygen saturations within a safe range on the amount of oxygen, they are receiving without it being changed. The test will cover the baby when they are sleeping, awake and alert, and during feeding so that a true picture can be seen.

Steroids - A group of drugs used in different ways on the neonatal unit. They may be given to a mother prior to the birth of a premature infant to help mature the lungs. They can be used to increase blood pressure in infants when other medication has not worked. They are also used for babies who have been ventilated for a long time and are struggling to extubate. Steroids in low doses can reduce swelling in the lungs.

Stridor - A word used to describe the noise a baby makes when breathing in due to a blockage in the upper airway, for example swelling.

Sucrose - for pain relief during procedures.

Suction - Used to clear secretions from the mouth and nose. Babies may have increased secretions in their mouth that they are unable to clear themselves due to medication or prematurity. If the baby has an ET tube, this will be suctioned to help clear secretions in the lungs.

Surfactant - A natural compound given shortly after birth to extremely preterm infants whose lungs have not yet developed and started producing their own surfactant. It may also be needed in babies born at term who are struggling with their breathing. This is only in certain situations, and it is at the medics' discretion. Surfactant lubricates the lung lining making it easier to breath in and out, preventing the lung from collapsing.

T

Tachycardia - When the heart rate is faster than the normal range. This can sometimes be because the baby is in pain or irritated, due to a drug they have been given, or because of a cardiac condition.

Tachypnoea - A faster than normal breathing rate.

TPN (total parental nutrition) - A solution that is given via a long line and contains everything a baby needs to grow. It is used when a baby is unable to have milk feeds or is not on enough milk to grow adequately due to illness or prematurity.

Transfusion - When a solution such as platelets, red blood cells or plasma is transferred into the baby's vein by a cannula.

Trophic feeds - Milk feeds that are not counted in the baby's total fluid intake but are given to help prepare the gut for bigger feeds.

U

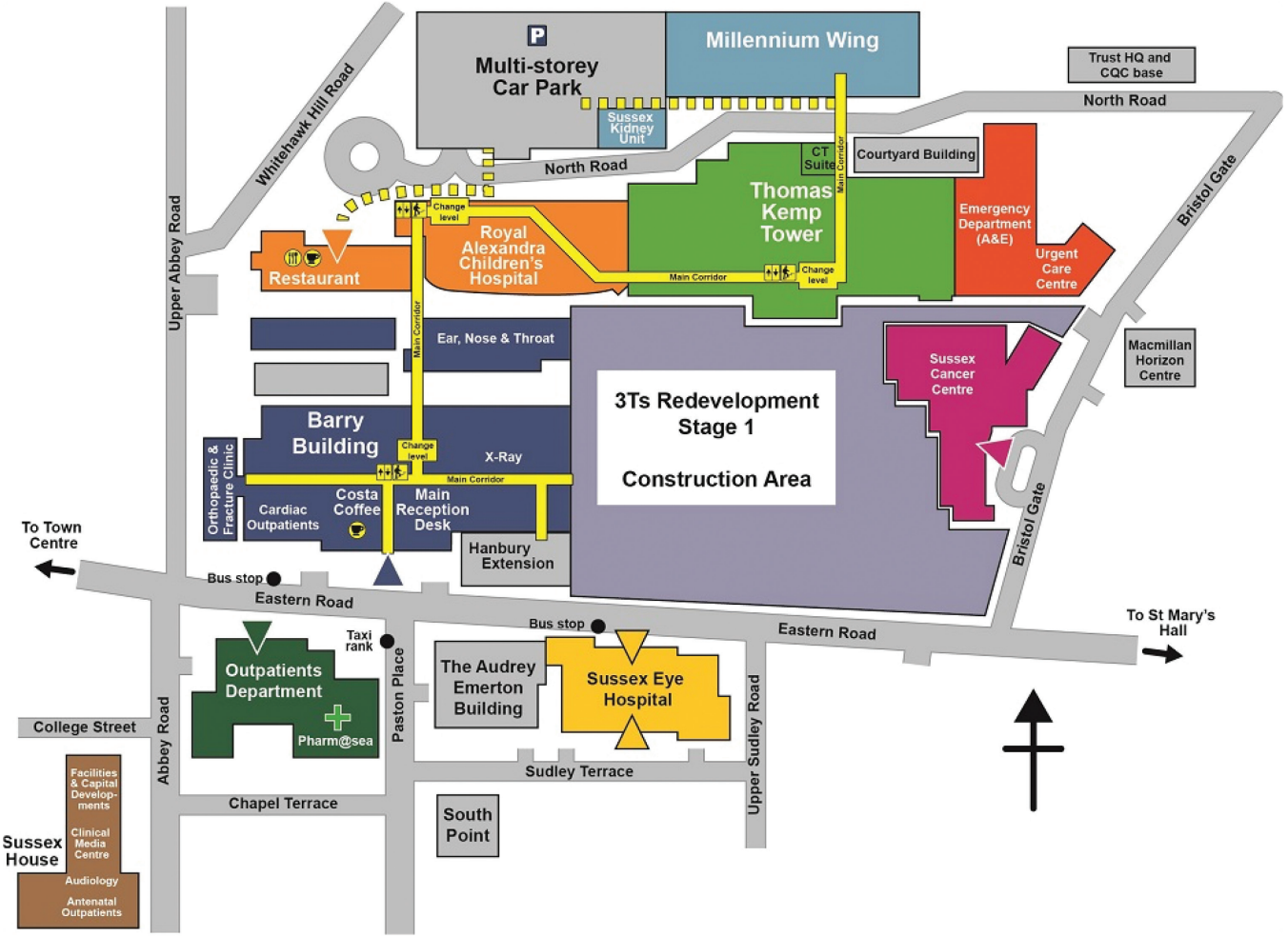
Umbilical catheter - A soft plastic line similar to that placed in the vein for a long line that is inserted into an umbilical artery or vein. Catheters inserted into the artery can be used to continuously measure blood pressure and take blood samples without the need for needles. A catheter inserted into an umbilical vein is used to give medications and fluids in the first few days of life.

V

Ventilation - Mechanical support with breathing to achieve normal levels of oxygen in the blood. There are several different types of ventilation.

Vitamin K - This vitamin is naturally occurring; however newborn babies often do not produce enough themselves so are given an injection into the thigh at birth. Vitamin K is important for the clotting of blood. Babies may need further doses of vitamin k given through the vein.

Royal Sussex County Hospital map



Princess Royal Hospital map

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