

## Consent in the Special Care Unit

Neonatal Services  
Tel: 01271 322610

### Other formats

If you need this information in another format such as audio CD, Braille, large print, high contrast, British Sign Language or translated into another language, please contact the PALS desk on 01271 314090 or at [ndht.pals@nhs.net](mailto:ndht.pals@nhs.net).

### Dear parents,

Your baby has been admitted to the Special Care Unit (SCU) because he/she requires extra and specialist care that cannot be provided on the general post-natal ward.

You, your family and friends may find this experience very difficult and distressing. You may be feeling very shocked or have a sense of loss that this has happened. It may be very different to the birth you were expecting. We will do our best to support you during this time and for the duration of your baby's stay on the unit.

The SCU team work very hard to make sure you are clear about what tests and treatments your baby will need. We will give you the information about your baby's condition and discuss the options available for the best treatment. With this help, guidance and information we hope you will feel better able to make decisions and give informed consent for your baby's care whilst on the unit.

Rest assured that we are always working to do the best for your baby.

Please take the time to read the information below. If there is anything you do not understand, please ask.

Once you are happy with the information provided, we would be grateful if you could fill in the consent form at the end of the leaflet and hand it into a nurse as soon as possible.

Yours faithfully,

The staff of the Special Care Unit

## **What is consent?**

'Consent' means giving your agreement or permission to the SCU staff to care for and treat your baby. We will give you written and verbal information so you can understand your baby's condition and the treatment/tests required. You will be able to ask questions at any time. Then you will be able to make a decision about your baby's care.

There are some treatments and investigations for which we will specifically seek consent. Some of these require your signature on a form. This does not necessarily mean that these are more important, but simply reflects a different consent process.

Remember – please ask if you are in any doubt.

## **What are the legal aspects of consent?**

Consent is obtained from someone with 'parental responsibility' and involves both communication and understanding by the parent. If parents are married, valid consent can be obtained from either parent. If the parents are not married, consent is obtained from the mother by default. The father is able to provide valid consent only if he is to be named on the birth certificate and the mother confirms she wishes him to have parental responsibility.

## **Will there be times when you perform procedures and make decisions about my baby without my consent?**

Occasionally, in the case of emergencies or if you are unavailable, we may need to start investigations and treatment before we have a chance to talk to you. This might be when your baby is first admitted to the ward, for example. At all times, we will consider what is best for your baby and will always contact you as soon as possible, once your baby is more stable.

We will always try to discuss your baby's condition with you and keep you informed of what we propose for your baby, and ask for your consent (agreement) for that.

## **What if I do not agree with the SCU staff recommendations and advice?**

If there is disagreement about what is recommended, we will respect your opinion and try to work out another plan. You may go to Patient Advice and Liaison Services (PALS) for advice (see below), or call BLISS Family Support Helpline on 0500 618140.

Very occasionally, second opinions may be sought by either party.

## **Do I need to give consent for everything that happens to my baby?**

Our paediatric doctors use national guidance for the consent required from the British Association of Perinatal Medicine.

We want your consent for the procedures required to care for your baby.

However, when you have left the baby in our care, you agree to routine procedures such as feeding your baby, taking blood for basic tests or conducting x-rays where necessary.

On SCU, we provide a lot of routine care for your baby.

'Routine' care involves many procedures and treatments which are not routine elsewhere, but which are necessary for your baby at this time. We would ask you to give us permission to perform these routine procedures when your baby needs them, even if you are not available, so that your baby's care can continue.

## Visiting

You and your partner can visit your baby at any time day or night. Two visitors can also visit with you throughout the day (as is reasonable), apart from quiet time between 12noon and 2pm which is for parents only. Normally we would not let any visitors in without you being present. If you are happy for anyone to visit whilst you are not here, please write their details on the consent form (last page of this document).

## How do we let the staff know our decisions?

You can speak to us at any time or phone us on 01271 322610.

On the baby's cot-side there is a pink or blue communication card. Please feel free to write down your decisions/plans for the baby, for example, who is allowed to visit your baby or if your baby is allowed a dummy.

Once you have read this information leaflet, we will ask you to fill in the attached form to let us have your decisions and to give us consent for some of the 'routine' procedures described below.

## What are the routine care/procedures my baby may receive in SCU?

1. Monitoring
2. Blood tests
3. Intravenous infusions (drips)
4. Medications
5. Naso/oro-gastric tubes (feeding tubes)
6. Feeding
7. Sucrose
8. Use of dummies/pacifiers
9. X-rays
10. Phototherapy
11. Other routine procedures
12. Sharing information and use of the Badger computer system

These are explained more fully below, and appear on the consent form.

## **1. Monitoring**

To ensure your baby is well and to direct the nurses and doctors in his or her care it is routine practice to monitor your baby's condition. This may be the temperature, the heart rate, the breathing rate and the oxygen saturation levels (percentage of oxygen carried in the baby's blood). These monitors are sensitive and alarms will sound to alert us to changes in your baby's condition. However, they often sound when there are no concerns (for example when the baby moves). Please ask the nurses and doctors to discuss with you what are normal readings for your baby. We will remove the monitors as soon as they are not needed.

## **2. Blood tests**

When babies are unwell, samples of blood will be taken to check for things such as infection, anaemia, blood sugar, salt and jaundice levels. We always use the smallest amount of blood possible, and usually take it through a fine needle inserted into a vein from a heel prick or from an arterial line. We will ask your permission to give the baby sucrose for pain relief for these procedures. The doctors and nurses will discuss the reasons for the various tests we do and the results as these become available.

## **3. Intravenous infusions (drips)**

All babies need to have a certain amount of fluid each day, along with salts and sugar. If this need cannot be met by feeding the baby by mouth or a tube into the stomach, we insert a fine plastic tube (cannula) into a vein. This is usually on the hand, foot or at the elbow. Special infusion pumps control the fluid given, and we monitor the situation by weighing the baby and doing blood tests. We use the same type of cannula to give antibiotics and other drugs.

When your baby is newly-born, sometimes we are able to use umbilical vessels in your baby's cord for fluids, medication and monitoring.

## **4. Medications**

There are several medications that may be necessary to help your baby recover or protect them from complications which may occur. Some of these could be antibiotics, vitamins, painkillers, sedation, and medicines used in emergencies.

## **5. Naso/oro-gastric tubes**

If your baby is unable to feed properly because they are too unwell or born too early, we may wish to feed him/her by a plastic tube. This goes to the stomach from the mouth/nose. We can then feed them using your breast milk or a formula milk of your choice.

## **6. Feeding**

We will ask you how you want to feed your baby.

If you wish to breast-feed, then we have facilities for you to express and store your milk if your baby is unable to feed at first. Sometimes when you have not expressed enough milk, we may need to give your baby formula milk. This is better for the baby than having a drip. We will ask your permission for this and which formula you would prefer.

## **7. Sucrose (see separate parent information leaflet)**

We use sucrose for pain relief for small procedures such as blood taking.

## **8. Use of dummies/pacifiers (see separate parent information leaflet)**

We use dummies for pain relief, for a pleasurable experience, to settle your baby when you are not here, as a developmental aid to practice sucking and to help with continuous positive airways pressure (see below).

## **9. X-rays**

These are usually done on the SCU using a mobile x-ray machine. Most often we x-ray the chest to detect problems with the lungs and heart, or the abdomen to look at the intestines. We also do x-rays to look at the position of the tips of the various tubes we have inserted. The amount of radiation used for these x-rays is as low as possible, and we only do x-rays when they are needed to help us look after your baby.

## **10. Phototherapy**

Phototherapy is a blue light used to break down dangerous levels of a bile pigment called bilirubin in the blood. Babies sometimes need this if their liver cannot remove the bilirubin fast enough.

## **11. Other routine procedures**

Other procedures and treatments require you to give your consent either verbally, after discussion with a doctor/nurse, or, in cases such as surgery, hearing screening or immunisations, by completing a written consent form after having an opportunity to ask any questions. Naturally the doctors and nurses are happy to discuss the results of any test with you and we will endeavour to keep you fully informed at all times.

## **12. Sharing information and the Badger computer system**

We would like to ask your permission for information about your baby's stay in SCU to be collected alongside that for other babies receiving neonatal care in the region. This information is confidential and is collected on a computer system called Badger. By giving your permission, you will be helping the staff on this unit improve the care we provide for babies in the future.

We would also ask permission for us to be able to share information about your baby where it is needed to help us give your baby the treatment he or she needs. For example the doctors may wish to discuss your baby's care with a specialist baby doctor (a neonatologist).

## **13. vCreate**

vCreate is an NHS trusted secure video messaging service that enables the nursing team to send you short videos and photos of your child, during those times when you are unable to be on the unit.

Its aim is to provide you with some reassurance and to minimise any separation anxiety you're experiencing. We know it's not the same as being with your child but hopefully it's the next best thing.

## What other non-routine procedures might my baby receive?

There might be other tests and procedures that are less routine but are considered essential for your baby's care. These include the insertion of some longer intravenous or arterial lines, lumbar puncture, blood transfusions, screening for retinopathy (premature eye disease), more specialised x-rays and scans (such as CT or MRI scans), chest drains, continuous positive airways pressure and ventilation.

We will discuss these procedures with you beforehand and ask for your consent. There may be some rare situations where it is not possible to get your consent in time – usually in an emergency – but you will be informed of such an event as soon as possible.

### Procedures performed less often are:

1. Oxygen administration
2. Total parenteral nutrition
3. Long lines
4. Arterial lines
5. Continuous positive airway pressure (CPAP)
6. Ventilation
7. Lumbar puncture
8. Ultrasound scans
9. Blood transfusion
10. Chest drains
11. Cerebral function monitoring (CFAM)
12. Cooling

#### 1. Oxygen administration

When your baby is born he or she may need help to support his or her breathing. Sometimes we give oxygen to your baby to help with this. There are lots of reasons for this and the SCU team will be able to discuss this with you.

We can give oxygen in many different ways and this will be discussed with you.

#### 2. Total parenteral nutrition

We can also give intravenous feeding, often called TPN (total parenteral nutrition), through a cannula into a vein. This is intended to feed the baby rather than just to prevent dehydration, and will be started if the baby cannot be fed by mouth or tube into the stomach for more than a few days. For TPN we often insert a special type of plastic cannula called a 'long line'. This works in just the same way but is much longer and the tip lies in a large vein close to the heart. Although these lines carry some additional risks, they can also remain in place much longer which can be a major advantage for the baby.

### **3. Long lines**

See above.

### **4. Arterial lines**

We sometimes put these lines in to measure blood pressure and to take blood tests. This allows your baby to have procedures like blood tests without disturbance or distress. A fine plastic tube is inserted into an artery, usually at the wrist, ankle or umbilicus.

### **5. Continuous positive airway pressure (CPAP)**

Some babies require a bit of help with their breathing. They may be making a grunting noise, getting too tired to breathe or needing oxygen. This extra help can be given by CPAP. Air and oxygen flow through two fine tubes or a mask, placed in or over the baby's nostrils. This makes air pressure, helping to keep the lungs open.

### **6. Ventilation**

When babies need more help than CPAP for their breathing, they may require ventilation. Ventilator machines are used to let your baby rest from the struggle of breathing on their own. The machine works with your baby to give good breaths. It blows moist air enriched with oxygen gently into the baby's lungs when they breathe, via a tube that is passed through the mouth or nose into the windpipe (trachea).

### **7. Lumbar puncture**

We can take samples of spinal fluid by inserting a fine needle between the back bones in the lower part of the spine. It is uncomfortable for the baby but only for a few minutes. It is only done if essential – generally to check for possible infections surrounding the brain (meningitis). The test results are usually available within two and 24 hours, allowing us to change the baby's treatment if necessary, or to reassure you that all is well.

### **8. Ultrasound scans**

A mobile ultrasound machine is also in use on the neonatal unit. This is almost identical to the machines used on pregnant mothers to check on the baby's growth and position. We use it to check on the baby's brain, heart and sometimes other organs such as the liver, kidneys and bladder.

### **9. Blood transfusion**

Some newborn babies need blood transfusions. This is because the bone marrow that usually makes blood cells doesn't work very well in the first weeks after birth, particularly if the baby is ill or premature. The blood used for transfusion will have been thoroughly tested before it is given to your baby. We do not give blood unless necessary and will always try to discuss the reasons with you first, unless the transfusion is needed as an emergency to save the baby's life.

We sometimes just give the part or parts of the blood which the baby is lacking, for example, plasma to help improve circulation or blood clotting factors, or platelets where these are very low.

Very occasionally we need to do an 'exchange blood transfusion', which means that we slowly remove all of the baby's blood whilst slowly giving donor blood. This is usually done for dangerously high levels of jaundice.

## 10. Chest drains

Air can sometimes leak from damaged air sacs in the lungs. Large amounts of air leak may cause the lung around it to collapse. Chest drains are small tubes passed through the chest wall to let the air escape. If this has to be done as an emergency, the staff will discuss it with you as soon as they can.

## 11. Cerebral Function Monitoring (CFAM)

Sometimes the doctors need to check that the electrical impulses in the brain are all working normally, for example if your baby has had a difficult delivery.

## 12. Cooling

If your baby appears very poorly (this is usually following delivery) the doctors may feel that your baby should be cooled. We do not actively cool the baby in the Special Care Unit; we just do not put warm clothes on the baby and we do not heat the incubator. This is done to protect your baby's brain. If this is thought to be best for your baby it is started as soon as possible, then your baby's condition will be discussed with you and the Neonatal Intensive Care Unit (usually in Plymouth) to plan the best treatment.

## The Baby Friendly Initiative – Infant Feeding Survey

We are in the process of becoming fully accredited with **Unicef's Baby Friendly Initiative**. For more information about this, please visit: [www.unicef.org.uk/babyfriendly](http://www.unicef.org.uk/babyfriendly)

As part of our work to become fully accredited, we would like to know about your experience with our neonatal services through a survey. The survey will help us understand if we have supported mothers and babies with their infant feeding choices and encouraged the development of close and loving relationships between parents and their baby.

It will involve a telephone conversation which should take about 10 minutes. The information you provide will be used to update staff training and will improve care for families in the future.

It is optional to take part and your choice will not affect your care. You can change your mind at any time. Not all parents will be contacted. Your answers will be completely anonymous and your health professionals will not know what you, as an individual, have said.

## I've read all this but there are things I still don't understand!

Please speak to a member of the SCU team. We are pleased to answer your questions and we will be able to find out more information if you want it.



## Further information

### BLISS the Premature Baby Charity

Freephone: 0500 618140 Email: [information@bliss.org.uk](mailto:information@bliss.org.uk)

Website: [www.bliss.org.uk/](http://www.bliss.org.uk/)

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### **PALS**

The Patient Advice and Liaison Service (PALS) ensures that the NHS listens to patients, relatives, carers and friends, answers questions and resolves concerns as quickly as possible. If you have a query or concern call 01271 314090 or email [ndht.pals@nhs.net](mailto:ndht.pals@nhs.net). You can also visit the PALS and Information Centre in person at North Devon District Hospital, Barnstaple.

## Have your say

Northern Devon Healthcare NHS Trust aims to provide high quality services. However, please tell us when something could be improved. If you have a comment or compliment about a service or treatment, please raise your comments with a member of staff or the PALS team in the first instance.

'Care Opinion' comments forms are on all wards or online at  
[www.careopinion.org.uk](http://www.careopinion.org.uk). Northern Devon Healthcare NHS Trust  
Raleigh Park, Barnstaple  
Devon EX31 4JB  
Tel. 01271 322577  
[www.northdevonhealth.nhs.uk](http://www.northdevonhealth.nhs.uk)

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**Name of baby** .....

Patient's ID Label may be used

(If you have twins you will need to fill this out for both babies.)

## Form for parental consent to treatment of their baby on the Special Care Unit

Dear Parents,

Please could you read and fill in this form after reading the parental information on consent and then give it to a member of staff.

	Please delete	
I have read and understood the parent information leaflet on consent	Yes	No
I wish my baby to be	Breast fed	Bottle fed
If my breast milk is unavailable, I am happy for my baby to receive formula milk.	Yes	No
The formula I would prefer is		
I am happy for my baby to have sucrose for pain relief.	Yes	No
I am happy for my baby to have a dummy.	Yes	No
I am happy for my baby's health details to be collected confidentially on the Badger system to help future care on neonatal units. I consent for details about my baby to be shared.	Yes	No
I consent to take part in the BFI Infant Feeding Survey	Yes	No

I (the parent) have been given information on the routine procedures listed overleaf. I agree to my baby undergoing these routine procedures if it is needed during my baby's stay on the Special Care Unit.

These routine care/procedures may be:

- Monitoring
- Blood tests
- Intravenous (IV) drip
- Medicines
- Phototherapy – (light treatment for jaundice)
- Naso/orogastric tube insertion
- Feeding with formula
- X rays
- Phototherapy
- Other (please fill in)

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Please state any care/procedures you are not happy about or require more information.

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Please state if anyone can visit your baby if you are not present.

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Signed \_\_\_\_\_ (mother/father/carer)

Print name \_\_\_\_\_

Date \_\_\_\_\_