# Patent Ductus Arteriosus (PDA) in premature babies

Information for parents and carers





# About this booklet

You have been given this booklet because your baby may have a persistent patent ductus arteriosus (PDA). You might hear this referred to as a 'duct'.

We'll try and answer the common questions that parents have about PDA, but you are encouraged to talk more about this with the team looking after your baby who will be happy to discuss this in more detail and answer any questions you may have.

## What is a PDA?

#### The normal heart

All babies are born with a patent (open) ductus arteriosus, commonly called a 'duct'. This is a small muscular blood vessel that connects the aorta (the large blood vessel from the heart that supplies blood to the body) and the pulmonary artery (the blood vessel carrying blood from the heart to the lungs). This connection exists to allow most blood to be diverted away from the lungs whilst your baby develops in the womb because the lungs are not needed before birth and are filled with fluid.

In typical circumstances, once the baby is born and starts using their lungs to breathe, blood then needs to go to the lungs instead of bypassing through the ductus arteriosus. Because the duct is no longer needed it will usually close within the first few hours or days after birth.



Heart with PDA (duct open)

Heart with no PDA (duct closed)

rom Lunas

## Why might my baby have a PDA?

In some babies, the ductus arteriosus may remain open or can re-open after closing, and this is called a persistent patent ductus arteriosus or PDA. This is much more common in premature babies. The more premature the baby, the higher the risk of a PDA and the more likely it is that this will cause symptoms.

# How will this affect my baby?

A PDA can affect every baby differently but essentially, if the duct remains open after the baby is born, one of two things may happen:

- 1. Blood from the body gets shunted through the duct into the lungs causing excessive blood flow to the lungs.
- 2. Blood which would normally travel around the body is 'stolen' by the duct resulting in reduced blood flow to some organs of the body

The increased blood flow to the lungs may cause some breathing difficulties. These difficulties may be mild, like difficulty in maintaining stable blood oxygen saturations, short apnoeas (not breathing for a short period of time) or a slightly faster breathing rate. However, they do vary and for some babies with a PDA it can be difficult for them to breathe without a ventilator.

One other issue is that the heart may have to work harder to pump blood around the body. Your baby may have a heart murmur (an extra sound heard as the blood travels through the PDA). They may also have low blood pressure and may need support with medication to help this.

Because blood is 'stolen' from other organs like the gut we sometimes find that babies with a PDA have difficulty establishing and tolerating milk feeds

The signs that your baby will have will depend on the size of the PDA. A baby with a small PDA may have no signs at all.

#### How can we confirm if our baby has a PDA?

If your doctor suspects that your baby may have a PDA then they will request a special ultrasound scan of the heart called an echocardiogram or 'echo'. This is much like ultrasound scans that you may have had or observed during pregnancy and is not painful for your baby. It is possible to look at the structure of the heart, nearby blood vessels and an assessment of PDA size and flow can be made if there is a PDA.

## How do we treat PDA?

Depending on how your baby is and the severity of the PDA, your doctors may choose one or more of the following options:

#### No treatment (conservative approach)

Not all babies that have a PDA will require treatment. If the PDA is small and your baby is making good progress, then the doctors may choose to just monitor the situation and see if the duct closes on its own.

#### Medication

If the PDA is causing more significant problems for your baby, then the doctors will weigh up the risks and benefits of the other different options available based on what they think is best for your baby.

To try and reduce how hard the heart and lungs have to work, the doctors may choose to reduce the total amount of fluid your baby is getting for a short time. They may also try using a diuretic, a water medication which helps remove extra fluid from the body by producing more urine.

If these measures do not help, then the doctors may choose to start a medication which has been shown to be effective in helping to close the duct in premature babies. The two different medications they may use are called paracetamol and ibuprofen. Which one the doctors choose will depend on the individual situation for your baby. Your baby will be closely monitored throughout the treatment which will usually last for a few days.

Your baby may need additional blood tests to monitor for possible side effects of the medication which can temporarily affect how your baby's kidneys, gut, liver and platelets (part of the blood that helps you stop bleeding) work. These effects are usually reversible.

The medication may close the PDA or make it smaller. The doctors will look for changes in your baby's clinical condition in response to treatment and may repeat the echo to reassess the size of the duct, if appropriate. Multiple courses of medical treatment can be given if needed.

#### Surgical

For a small number of babies with PDA, especially those with a larger PDA, these medical measures may not be sufficient on their own to close the duct or reduce its size to restrict the flow through the duct. Or it may occasionally be the case that your baby is not suitable for treatment with medication due to other medical problems. If the PDA is still causing significant problems, the doctors may recommend an operation to close the PDA for these babies. If surgery is being considered, then the decision will be made in consultation with the heart specialists in Southampton Children's Hospital. For more information see the 'Surgical treatment for PDA' information leaflet.

If you have any further questions about any of these treatment options, the doctors caring for your baby will be able to discuss them with you in more detail.

# Surgical treatment for Patent Ductus Arteriosus (PDA) in premature babies

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## Surgical treatment of PDA

The surgery will be carried out by specialist heart surgeons at Southampton Children's Hospital who treat all the different types of heart conditions that can happen in babies.

The idea of your baby having surgery may seem like a very scary thought, but the surgery to treat a PDA is usually successful and babies recover quickly. Remember, the doctors wouldn't suggest surgery unless it was felt to be necessary for your baby.

### The operation

Your baby's surgery will usually happen on the neonatal intensive care unit in Princess Anne Hospital.

Your baby will receive anaesthetic for the procedure.

The operation is performed through a small incision (cut) in the left side of the chest. The incision is usually about 2-3 cm long.

Through this incision the lung is gently pushed out of the way so that the surgeon can get to the main blood vessels and the duct connecting them together.

The duct is then tied off with a ligature or tiny clip (the clip is compatible with body scanners in hospitals and other locations such as airports).



Once the duct has been tied off the skin is stitched together with invisible stitches that dissolve.

# What are the risks of the operation?

All surgery has minor risks, either related to the anaesthetic or the procedure itself.

If you have concerns about the anaesthetic, then then anaesthetist will be happy to discuss these with you in more detail.

The surgery itself is a relatively straightforward procedure that is commonly performed and relatively safe. The risks are therefore relatively low. In Southampton, the risk of your preterm baby not surviving the surgery is around 1 %.

However, it is important that you understand that it is a major operation involving the major blood vessels inside the chest. Your baby is small and fragile, and the surgery is delicate. There may be a short period after the operation when your baby requires more support than previously.

Sometimes the lung may not fully re-expand straight away after it has been moved out of the way for surgery. Occasionally this may mean that the surgeons need to leave a drain (small tube) in place to help drain any fluid out of the chest. Fewer than 1 in 20 (<5%) of babies would ever need a chest drain.

Your baby may experience other complications, but these are rare, and the heart specialists can go through these with you in more detail before the operation.

Your baby will have as small a scar as possible, and this generally heals very well.

Your baby may face many challenges related to their prematurity, but hopefully by closing the PDA this will help them cope better.

## What are the risks of not treating the PDA?

If the PDA does not close on its own and remains large, then not treating it can lead to high blood pressure in the lungs, which is called pulmonary hypertension. It can also increase the risk of the gut condition, necrotising enterocolitis.

Babies who need surgery to close a PDA may already have existing conditions linked to their prematurity. Not treating a PDA may put them at a higher risk of developing conditions of their lungs such as Chronic Lung Disease (CLD).

# Long term effects and follow-up

Most babies who have a PDA will need no further treatment for it once it is successfully closed.

Your baby will be followed up by their local team following their discharge from hospital. The neonatologist or paediatrician will monitor their growth and development. There is no need for any cardiac follow-up appointments.

# Practicalities

### Why can't it be done in my local hospital?

All heart surgery is carried out at Southampton Children's Hospital where there are specialist facilities and staff including experienced heart surgeons who regularly perform the procedure. This is usually undertaken on the Neonatal Intensive Care unit in Princess Anne Hospital which is part of Southampton Children's Hospital.





## What if my baby is not in Southampton?

If your baby is not already in Southampton, then your baby will be taken to the Southampton Neonatal Intensive Care Unit by the Southampton Oxford Neonatal Transport team (SONeT).



For further information regarding the SONeT team please use the link below:

https://www.sort.nhs.uk/SONeT/Patientandfamily/Patientandfamily.aspx

Once your baby is in Southampton, you will have an opportunity to meet the team which includes the neonatologists, cardiologist and cardiothoracic surgeons. Your baby will have further assessment by the team to ensure that PDA surgery is still needed. If you baby does have PDA surgery, then once the operation is complete, your baby will be taken back to your local hospital for ongoing care as soon as it is safe to do so.

# Where is Southampton Neonatal Intensive Care Unit?



Southampton Neonatal Intensive Care Unit D Floor, Princess Anne Hospital Coxford Road Southampton SO16 5YA

023 8120 6001

For more information please see the link below to an interactive video to help you understand what to expect when you arrive on the unit as well as helping you to find your way around:

https://www.uhs.nhs.uk/for-visitors/southampton-childrens-hospital/childrensservices/neonatal-intensive-care-unit/neonatal-unit-tour

The unit has open visiting hours for parents who can visit at any time. There have been regular changes to visiting for siblings and extended family in response to the coronavirus pandemic so we would encourage you to ask the team on arrival to confirm the current policy.

#### Where can we stay?

Your baby will be on the neonatal unit and once you arrive in Southampton the team there can arrange accommodation for you should you require it. This will usually be at Ronald MacDonald House, which is charitable accommodation nearby.



Ronald McDonald House Southampton

# What will happen before the operation?

If your baby has come from a unit other than Southampton, then your baby may well undergo a further assessment by the neonatal and cardiology team on arrival which usually includes a further echocardiogram

The anaesthetist will also come and review your baby prior to the surgery.

The surgery is performed under anaesthetic so if your baby does not already have a breathing tube then this will be done before surgery commences.

#### Will I meet the heart surgeons before the operation?

You will have the opportunity to meet with the specialist heart surgeons prior to the operation. You will have a chance to discuss the surgery and ask any questions you may have. You will also need to sign the consent form ahead of the procedure.

The procedure itself is done on the neonatal intensive care unit and usually lasts around 30 minutes to an hour. You are welcome to wait in the parents' room and the team can contact you once the surgery is finished.

### How long will it take my baby to recover?

The recovery from the surgery is variable and will depend on how well your baby was prior to the procedure and any other complications they may have experienced from their prematurity. Generally, your baby will have recovered from the procedure itself within a couple of days.

If your baby was transferred to Southampton from another hospital, then your baby will only need to remain there until they are stable following the operation. They can then return to receive their ongoing care from their local unit. If there are no other concerns or complications this usually happens within the first 24 hours after the operation.





# Support for parents and carers

If at any point you have questions or concerns about any aspects of your baby's care or treatment, please do speak to a member of staff on the neonatal intensive care unit who will always be happy to help.

You may also contact the Cardiac Nurse Specialists on 023 8120 4659 (Monday to Friday 09:00 – 17:00)

# Sharing information about your baby

Information is collected about your baby relevant to their diagnosis, treatment and care. It is stored in written and computer-based electronic records. As a necessary part of that care and treatment we may need to share some of your information with other people or organisations who are involved in your baby's care. If you are not happy with this, then please discuss this with the team looking after your baby.



#### National Congenital Heart Disease Audit (NCHDA) and National Institute of Cardiovascular Outcomes and Research (NICOR)

NCHDA is a national database that gathers information about all cardiac surgery to make sure that it is performed to the same high quality across the UK. It is a government requirement that hospitals monitor how they are performing, and this data is used to independently check performance and ensure high levels of care are maintained. This database contains basic demographic information about your child such as their name, age and postcode and details about their condition and treatment.

## Interpreting services

There is an interpreting service available at Southampton Children's Hospital. If you need an interpreter, please let the team know so that they can arrange for any conversations with the medical teams to be translated into the appropriate language.

Neonatal Unit Princess Anne Hospital Coxford Road Southampton SO16 5YA

Neonatal Unit 023 8120 6001 (24 hours) Cardiac nurse specialists 023 8120 4659 (Monday to Friday 09:00 – 17:00)

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