

# Too small too soon

## Information for parents of babies born at around 25 weeks

You have been given this information because your doctors think that you may have your baby very soon. You and your family need to know about what might happen for your baby.

A normal pregnancy lasts for 40 weeks. Babies born after only 25 weeks are small and fragile. With intensive medical treatment most babies survive, but some do not.

As the chances for babies born this early are pretty good, doctors usually provide intensive treatment and see how the baby responds.

## *Patient Information Booklet*

## What is likely to happen?

For babies born at 25 or 26 weeks the chance of survival if they receive intensive treatment is about 80%.

Babies will need help with their breathing and spend time in a Neonatal Intensive Care Unit (NICU). They can be quite sick for a few days and may need help with their breathing for quite a while.

Babies born this early can have problems while they are very small and problems later in life if they survive. Your baby might have none or several of these problems. Most children do not have serious disabilities later in life. But a small number do, and it is important to know what this means.

These pages have more information on what is likely to happen.

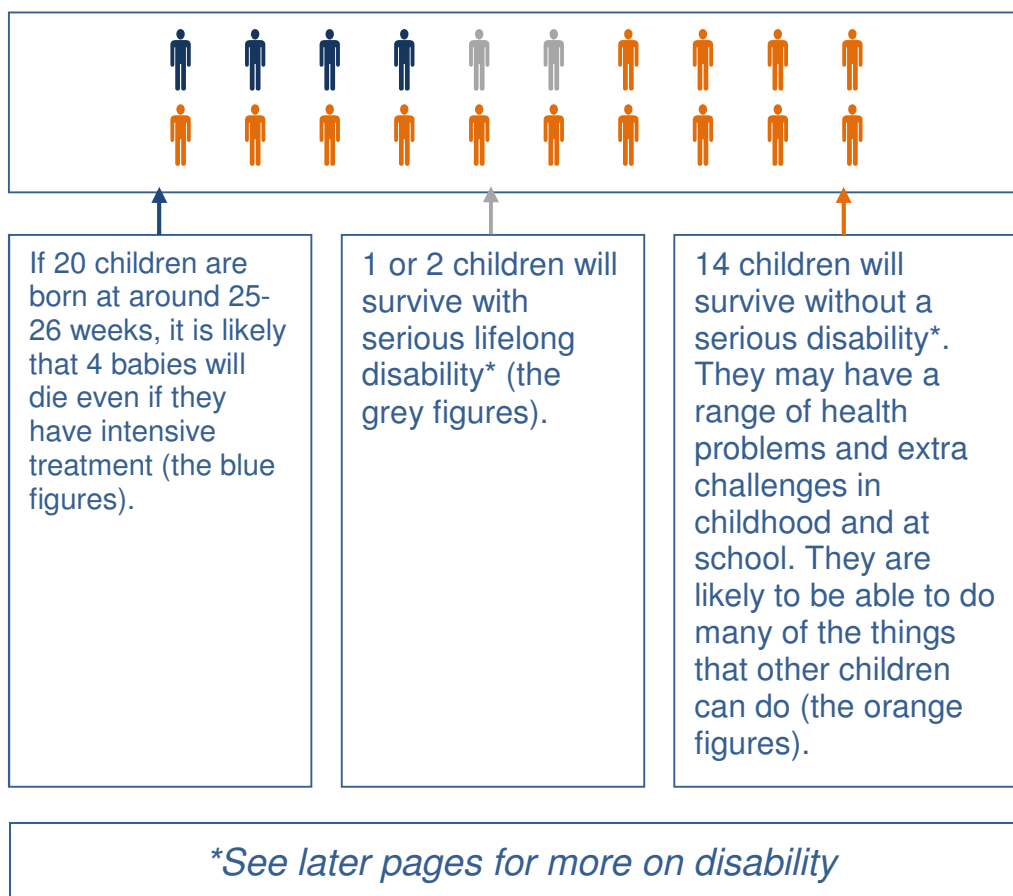
**It is important to talk with your doctors. They will give you more information about your own situation.**

## NOTES:

## The big picture

For babies born at 25 or 26 weeks the chance of survival if they receive intensive treatment is about 80%.

If the baby survives they may have one or more of the problems described below. The problems might be just while they are small, or they may be lifelong. About 1 in 10 children who survive have very serious problems affecting their movement (cerebral palsy) or learning or both, this means they will need lifelong help and support for everyday activities. **Most children born this early do not have serious disabilities later in life.** The diagram below shows this big picture.



We don't know what will happen for your child. The chances for your baby may be better than these figures or they may be worse – your doctor can give you some idea.

## When your baby is born

Doctors and nurses from the neonatal unit will be there when your baby is born. They will quickly take your baby to an area in the delivery room or the operating suite where they can be cared for.

Your baby will be specially wrapped to keep them warm. They will have an oxygen mask put on their face to help them breathe and inflate their lungs. They may have a breathing tube put in their nose or mouth. Once this is done the doctors can give them some medicine to help their lungs work better. If your baby is breathing well on their own, they may not need a breathing tube. They may have a constant flow of oxygen through small prongs in their nose (called CPAP or “High Flow”).

If possible you would have a chance to see and touch your baby before they are taken to the NICU. If there is no NICU in your hospital a special transport team will take him or her to a large hospital where they can be cared for.

In the NICU your baby would be connected to life support with a breathing machine. They would be connected to wires measuring their oxygen, heartbeat and blood pressure. They would have a feeding tube in their nose. They may need two tubes in their blood vessels to give medicines and take blood samples. To start with these tubes are often placed in the baby’s belly button, but they might be in their hands or feet. The baby would be given medicine if they appear to be uncomfortable or in pain.

## **Intensive treatment**

Doctors always think carefully about whether intensive treatment will help the patient or do more harm than good. Most babies born this early respond well to intensive treatment. But if your baby is not responding, or develops a serious problem (e.g. bleeding in the brain) doctors will talk to you about whether intensive treatment is still the right thing to do.

## **What will happen in the NICU?**

### **Feeding**

Babies born this early can be quite sick for a few days after birth. While they are sick they may not take much milk. In a couple of days doctors usually start giving a small amount of milk.

The best food for very premature babies is breast milk. Babies born this early cannot suck milk from the breast yet. Mothers can pump (‘express’) the milk to give them. Expressed milk can be given through a tube into the baby’s stomach, or it can be frozen until the baby is ready for it. Midwives can show you how to express your milk. It may take a few days for the milk to come. If you are not able to express, or decide not to, your baby could have formula milk.

Until your baby is able to take enough milk, doctors will give them special food directly into their bloodstream. This helps them to grow and not feel hungry. Babies usually need a special thin tube in a blood vessel for this food.

## **Breathing**

Babies may need some help with their breathing for a while. They will have blood tests to see how their breathing is going, and to check their salt and sugar levels. Blood tests are often done using a small prick of the baby's foot. If your baby needs lots of blood tests they may have a special tube put into an artery so they don't need as many needles.

As your baby gets bigger and stronger they need less help from breathing machines, less blood tests, and less wires and tubes. When they are stable they will move out of the NICU into the Special Care Nursery.

It is likely that your baby will need to stay in hospital until close to when they were due. This is usually around 37 weeks, but is sometimes earlier or later.

## **Problems for premature babies**

Babies born this early often have some problems. There are problems that affect them mostly while they are very small, and there are others that can affect them later in life, if they survive. Your baby might have none of these problems or several of them.

## **Problems in the NICU**

### **Lung problems**

Babies born this early can be very sick because their lungs are small and immature. At only 25 or 26 weeks the lung sacs that are important for breathing have only just developed. Some babies cannot get enough oxygen because of this. Other babies develop scarring or damage to their lungs. The machines that help babies to breathe can sometimes lead to stretching, or tearing of their fragile lung sacs. Babies who develop scarring of their lung (called bronchopulmonary dysplasia - BPD) can improve with time, but may need extra oxygen and help with their breathing for the first weeks or months. About 1 in 2 babies born this early develop BPD.

### **Heart problems**

Babies may have problems with low blood pressure after birth, and poor supply of blood to their body. They may need medicines to help their blood pressure. They may have problems with a blood vessel next to the heart (the 'duct'). The duct normally closes after birth, but in premature babies may stay open. Babies often receive medicines to help the duct to close, and some need surgery.

### **Brain problems**

Babies born this early may develop damage to their brain because of problems with the supply of oxygen and blood. Some babies develop areas of bleeding in the middle of their brain. This is called 'intraventricular haemorrhage' or IVH. It can be picked up on an ultrasound of the baby's brain. Mild forms of IVH may not be a big

problem. More severe bleeding increases the chance that the baby will have serious learning or movement problems when they are older if they survive. Babies can also develop damage to the brain from lack of oxygen that is hard to see on ultrasound. It may show up later as cysts or 'holes'. About 1 or 2 in 10 babies born this early develop a significant early brain problem.

### **Eye problems**

The back of the eye is still growing and developing for babies born very early. As a result of being born so soon, being sick, and needing extra oxygen, some babies develop a problem where the blood vessels at the back of their eyes grow too fast ('retinopathy'). This can affect their vision later. About 1 to 2 in 10 babies have serious problems with retinopathy and need laser treatment to one or both of their eyes.

### **Infections of blood or bowel**

Babies born this early have problems because their immune system is not very strong. They are sensitive to infection. Infection can enter the bloodstream or it can affect organs such as the bowel. Serious infections can be life threatening. Infections of the bowel may mean that the baby needs surgery to remove part of their bowel. Serious bowel infections affect about 1 in 15 babies.

### **Problems later in life**

Most parents want to know whether their baby will have long term health problems or disabilities if they survive, and how bad these would be. **Most children born this early do not have serious disabilities later in life. But a small number do.** There are different types of problems that can affect babies who were born very early.

### **Problems with movement**

Damage to the baby's brain from being born so early can lead to them having problems with their movement later in life. Their muscles can be stiff or hard to control (called 'cerebral palsy'). Cerebral palsy varies. It can be quite mild. For example, the child might have trouble moving one hand or one leg, but have no trouble moving other parts of their body. Children with mild cerebral palsy are able to do most things like other children and go to a regular school. Or, cerebral palsy can be much more severe. Some children have problems affecting all of the muscles in their body. They may not be able to walk. They may need others to help them with most or all of their everyday needs.

About 1 in 10 children who have been born this early, and who survive, have cerebral palsy. Most of these children have one of the less serious forms of cerebral palsy.

## Problems with learning

A baby's brain is still growing and developing in the last months of pregnancy. For the premature baby this has to occur outside the womb when they may be very sick. Children who have been born this early may be slower with their learning and development than children who were born on time. Many will need some extra help with their school work. Problems with attention and behaviour are also more common. Learning problems can be mild, or they can be much more severe affecting the child's ability to communicate, care for themselves, and later on, live independently. Most learning problems in children who were born very early are mild or moderate. About 1 in 15 children who survive has a severe learning disability.

## Disability

Most children born this early do not have serious disabilities later in life. But a small number do, and it is important to know what this means.

'Disability' means a problem that affects someone's ability to do everyday things. There is a wide range of disabilities. It might affect just one part of a person's life (e.g. sight), or it might affect many of the things that the person does. A disability might be very mild or very severe.

Sometimes parents find the possibility that their child might have a disability scary or very upsetting. But it is important to know that with support people with disabilities are often able to do most things just as well (or better) than people without disabilities. And most people with disabilities report being generally happy with their life. How much a person is affected by their disability can depend a lot on how much support they can get.

When we talk about serious lifelong disabilities or severe disability we are referring to movement problems (cerebral palsy) that mean that a child is not likely to ever be able to walk. We are also referring to learning problems that mean that the child has major limitations with caring for themselves, communicating and getting around. Children with severe learning disability may be able to have some basic conversations, or they may have very limited or no ability to communicate. They may be able to learn some everyday tasks (getting dressed, toileting, feeding), or may be fully dependent on others. They may be able to live in supported accommodation when they are adults, or may need full-time care. Some children have both severe movement and severe learning problems.

## What if my baby doesn't come now?

If your baby does not come in the next day or two their chances will hopefully become even better. It's best if they stay in the womb for as long as possible.

## For more information

You can talk to your doctor, midwife or nurse any time you have questions. These services may also be able to help:

### **BLISS**

Premature baby charity

<http://www.bliss.org.uk/>

Telephone: 0500 618140

### **SANDS**

Stillbirth and neonatal death charity

<https://www.uk-sands.org/>

Telephone 020 7436 5881

***Patient Information Booklet compiled by:***

*Dr Dominic Wilkinson*

*Consultant Neonatologist*

*Oxford University Hospitals NHS Trust*

South East Coast Neonatal Network would like to thank Dr Dominic Wilkinson and Thames Valley and Wessex Neonatal Network for allowing us to adopt their booklet.

*14 December 2015*