



Periventricular leukomalacia

This information sheet from Great Ormond Street Hospital (GOSH) explains the causes, symptoms and treatment of periventricular leukomalacia (PVL) and where to get help.

Periventricular leukomalacia (PVL) is a type of brain injury that is most common in babies born too soon (premature) or at low birthweight. The white matter (leuko) surrounding the ventricles of the brain (periventricular) is deprived of blood and oxygen leading to softening (malacia). The white matter is responsible for transmitting messages from nerve cells in the brain so damage to the white matter can cause problems with movement and other body functions.

What causes periventricular leukomalacia?

While a baby is developing in the womb, their brain is developing too and needs a good supply of nutrients, blood and oxygen. If the blood supply to an area of the brain is stopped or reduces, this causes tissue damage. We do not know what causes this reduced blood flow but it seems to be more common if a baby has already had a bleed in the brain (intraventricular haemorrhage). It also seems to be linked to uterine (womb) infections and early rupture of the amniotic sac (waters breaking). It is also more common in babies born prematurely or with very low birthweight.

What are the signs and symptoms of periventricular leukomalacia?

It is not usually obvious at birth that a baby has periventricular leukomalacia, as the signs and symptoms start to show at around one to two years old. The degree to which a child is affected depends on the amount of brain tissue that has been damaged.

The most common symptom is cerebral palsy, a condition that affects coordination and movement. Cerebral palsy is a very variable condition – some children may only have minor movement problems but others may have severe disabilities. Children with periventricular leukomalacia may also have visual problems and/or learning disabilities.

How is periventricular leukomalacia diagnosed?

Periventricular leukomalacia tends to be suspected in babies born prematurely or at low birthweight, so they may be checked soon after birth before any symptoms start to show. They may have a cranial ultrasound scan – this is similar to the ultrasound scans carried out in pregnancy but the probe is held over the soft spot on the top of the head (fontanelle). Another imaging scan that might be suggested is an MRI scan – this shows the characteristic appearance of the condition.



How is periventricular leukomalacia treated?

Periventricular leukomalacia itself cannot be treated but much can be done to help improve the symptoms. Depending on the degree to which a child is affected, they may benefit from physiotherapy input to maintain as much movement as possible and occupational therapy if adaptations are needed for day to day activities. Speech and language support will help if speech or language problems become apparent. Support for any visual impairment such as glasses or low vision aids can also be helpful.

What happens next?

The outlook for children born with periventricular leukomalacia depends on the amount of brain tissue damaged – some children will have minimal problems but others may have severe disabilities. Periventricular leukomalacia is not a progressive disease, that is, it will not get any worse as a child grows older.

Further information and support

Bliss – the Special Care Baby Charity will be able to give you advice and support. Call their family support helpline on 0500 618 140 or visit their website at www.bliss.org.uk.

Scope is the main UK charity for people with cerebral palsy – call their helpline on 0808 800 3333 or visit their website at www.scope.org.uk.