

Children and PH

Unfortunately, there is no minimum age for PH sufferers. Not only is it seen in adults of all ages, but it can be found in the newborn, young children, teenagers and in early adulthood as well. In children however, the prognosis, treatments, investigations and overall needs can differ greatly from adults.

However, perhaps one of the most important things to bear in mind in children with PH is the need for the parents to be the child's advocate, spokesperson and carer.

The symptoms of PH for children are similar to that of an adult, though children are more likely to experience tiredness, dizziness and breathlessness and for many fainting is common (see Summary). They can fail to put on weight like a normal child. Children may also experience other unique problems such as slowed growth.

Tests carried out look for long standing blood clots in the lungs (which can often be seen in adults with PH) are rarely required in childhood. Children tend to be diagnosed earlier than adults, but just like adults they are often misdiagnosed several times before a correct diagnosis is made. The commonest misdiagnosis is asthma.

Severe, sustained PH is potentially fatal in any patient. Untreated PH in children worsens more quickly than the same condition in adults. Children also change more quickly than adults and the doctors have to watch them more closely and be ready to change the treatment if the child is not doing well. However, with treatment, children appear to have an overall better prognosis than adults. In the past decade or so, we have seen that a more positive and aggressive approach to the overall management of pulmonary hypertension in children has evolved. Recent advances in genetics and newer understandings in cell biology are providing fresh insights into the nature of this disease and new therapies offer an improved quality of life and increased survival in both adults and children.

Children are responsive to the same treatments as adults. Treatment for PH is life-long. The treatment used has to be individualized and adjusted according to how the child is responding. Children need close monitoring by a highly experienced PH team to ensure a satisfactory and sustained response to treatment. Optimizing management of the condition markedly improves quality of life and survival. Lung transplant is a treatment option considered in children with severe PH who are deteriorating despite maximal medical treatment.

In most cases, how your child is feeling is the best indicator of how well their body is coping with PH. A child with PH can still go to school, dance, play sports, ride a bike and unfortunately be just as naughty and infuriating as any other child! Just like other children (and adults for that matter), a child with PH can help themselves by eating a healthy and balanced diet and having rest periods. It is really important to have a greater degree of caution in allowing other non-PH doctors prescribe medication for a child with PH – if in doubt always ask your PH team. Make sure your child's dentist knows that they have PH. Never allow anyone to give your child a general anesthetic without telling the PH team so that they can get in contact with the anesthetist.

Herbal medicines should be used with caution as we understand little about them, and some have actually been shown to be harmful. Additionally, many children with PH will be taking warfarin or another drug to help "thin the blood" and these types of drugs can interact with a number of common prescription medications and over-the-counter medications. Again, if in doubt, ask your PH team!

Keeping it normal!

When a child has PH it can affect the whole family. The child, mum and dad, grandparents and other siblings may understandably all feel fed up and worried by the disease at times. It may be hard, but you should try to treat any child with PH as normally as possible. A child with PH will be happier if the rules stay the same and life carries on much the same as before. They will feel safe and just as loved as the rest of the family if they are treated just like the rest of the family. Children that are treated differently behave differently and a child with PH is only “different” in that they have an illness

As with any sick child, behavioral problems can crop up from time to time. Deal with them as soon as possible. For example, children when leaving hospital can be more demanding than usual. This can be a common reaction (it can even be seen in adults!), so you should be ready for it. Children just out of hospital can be clingier or may revert to earlier behavior such as bedwetting. Again, just ask you PH team for help or advice. Try hard not to forget other children in the family, they may feel upset at the extra attention that their brother or sister is being given. Make sure that friends and family are aware of the need not to pay less attention to your other children and ask that they treat them as equal.