



## Childs death from heart defects plummets

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**The British Heart Foundation has released figures that reveal a huge 83% drop in the number of children dying from congenital heart disease. News story from Australia's *The Reporter*:**

FIXING a child's heart is one the most intricate operations that the NHS performs.

Surgeons who do it must operate on tiny babies whose hearts are hardly bigger than walnuts and whose veins are little more than a hair's breadth across.

But despite the intricacy, it is something that surgeons, and in particular NHS surgeons, have quietly been getting better at for decades.

Today the British Heart Foundation has released figures that reveal a huge 83 per cent drop in the number of children dying from congenital heart disease - birth defects of the heart - over the last three decades.

Progress in diagnosis, intervention and post-op care has created a generation, now in their twenties and thirties, who are the first to have enjoyed high survival rates for major heart defects.

There are so many survivors that a new speciality - adult congenital heart monitoring - has emerged to treat them in later life.

"We are now getting generations of young people going into adulthood that wouldn't have done 20 or 30 years ago," Anne Keatley Clarke, chief executive of Children's Heart Federation, told *The Independent*.

"Children who had very complicated heart conditions are now going into their twenties or thirties, looking forward to leading a normal life.

"Thirty years ago parents were saying I just want my child to live. Now parents are saying, what's their quality of life going to be like?"

Around eight in every 1,000 babies is born with a heart defect - 12 every day in the UK.

The latest figures illustrate children's vastly improved chances. Between 1979 and 1983, more than 5,200 children lost their lives to congenital heart disease.

Between 2004 and 2008, that figure had plummeted to 893 and experts say it's still falling.

"It was once the case that patients with complex congenital heart disease would not be expected to survive," said Professor Andrew Taylor, a leading cardiologist at Great Ormond Street Hospital (GOSH).

"Nowadays it's completely the reverse. In our own institution we're looking at two to three per cent surgical mortality rates."

Progress in recent decades has been in four main areas: improved understanding of the anatomy of a child's heart, pioneered by the cardiologist Robert Anderson in the 1980s; better imaging, including the development of echocardiography and the cardiac MRI; new, often highly-complex surgical techniques; and the ever more sophisticated use of cardiac catheters, tubes which are fed into blood vessels in the arm or groin and can now be used to perform repairs - removing the need for risky open heart surgery.

In the area of diagnosis, imaging of children's hearts is now so sophisticated that a heart lesion can be detected in a 20-week old foetus in the womb, with a heart the size of a grape, beating 120 times per minute.

NHS cardiac surgery for children is provided at 10 hospitals around the country.

Despite the progress that was being made across the speciality at the time, child heart surgery was at the centre of one of the most notorious care failures of recent years - the 1990s Bristol heart scandal, in which scores of babies died because of substandard care at the Bristol Royal Infirmary.

The case galvanised even more rapid improvement across the sector, placing the impetus on surgeons to share their expertise across hospitals to ensure the NHS always provided the cutting edge.

The UK came to be seen by European cardiologists as the forefront of child heart surgery.

With only 10 specialist hospitals, surgeons at each unit would see more patients than they would in the smaller cardiac units in many European countries.

Alessandro Giardini, a consultant paediatric cardiologist at Great Ormond Street said the UK was "the place where you really wanted to be as a paediatric cardiologist" when he arrived from Italy six years ago.

Even in that time great leaps have been made, he said.

"Areas that had only acceptable survival rates - like hydroplastic left heart syndrome, when the child is born with only one pumping chamber - survival has improved in eight years from 60 to more than 85 per cent.

"For children with serious heart muscle problems, we have a range of technological tools that we did not have a few years ago.

"They are also improving survival rates. Very rarely now do we have to say to a parent: there is nothing we can do."

Researchers are now looking at the use of stem cells to create heart components that would grow as the patient grows, removing the need for follow-up operations.

Scientists are also investigating the molecular causes of heart defects in the womb, in the

hope of one day being able to prevent, rather than cure, child heart disease.

Controversy still exists over the number of specialist heart units in the UK.

Most experts now agree that better care can be provided by fewer, better-staffed, better-equipped and more specialist centres, but in June the Health Secretary Jeremy Hunt rejected plans to reduce the number of hospitals providing child heart surgery from 10 to seven, and sent the review panel back the drawing board.

Professor Peter Weissburg at British Heart Foundation said policymakers had to make a decision soon.

“We don’t want lots of mediocre centres, we want fewer really excellent centres.

“Our concern is the process has foundered somewhat. The longer it takes to come to a rational decision, the worse it is for children with congenital heart disease as centres can’t plan for the future, until they know what their future is.”

<http://www.thereporter.com.au/news/child-deaths-heart-defects-plummets/1...>