Indian Academy of Pediatrics (IAP)

GUIDELINES FOR PARENTS

Taking Care of My Child After Heart Surgery

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10 FAQs on TAKING CARE OF MY CHILD AFTER HEART SURGERY

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Taking Care of My Child After Heart Surgery

Q1

What should I do if I am told that my child has a heart defect. Will my child ever be normal and will he live a long life?

The most common heart defects are holes in the heart or communications which occur in areas of the heart which are normally closed. Accordingly, they are called atrial septal defect (ASD), ventricular septal defect (VSD), or patent ductus arteriosus (PDA). Other defects include narrowing of heart valves which obstruct flow of blood. Sometimes, as in tetralogy of Fallot—the most common cause of a blue baby—a hole and narrowing of a valve as well as nearby areas of the heart may occur together.

If you are told that your child has a heart defect, you should seek a good pediatric cardiologist or pediatric surgeon who will guide you about currently available operative and nonoperative options.

Many children with heart defects today after treatment lead long lives with a good quality life. So, as parents you should not be depressed or disheartened.

Q2

How should I care for my baby or child? What food can I give? Can I give normal vaccination?

- All newborn babies and infants should be breastfed. Many tend to tire easily, so feed at frequent intervals. Many vomit, so it is important to burp well after a feed and nurse in the lateral/side position, so that the baby does not choke on the vomit. Sometimes, they may need medicines to control frequent regurgitation or vomiting.
- Older children can be given normal food. Some infants need fluid restriction, so they should be preferentially given semisolids rather than large volumes of milk or juice.
- Many parents dilute milk. This should not be done, because then your baby gets less calories, and his weight gain will be very poor.

Children with untreated heart disease actually require more calories than normal children.

Normal vaccination can be given. However, if surgery has been done, then it is advisable to wait for 6 weeks after surgery to resume the vaccination schedule.

Q3

Can I bathe my baby? Will he get pneumonia?

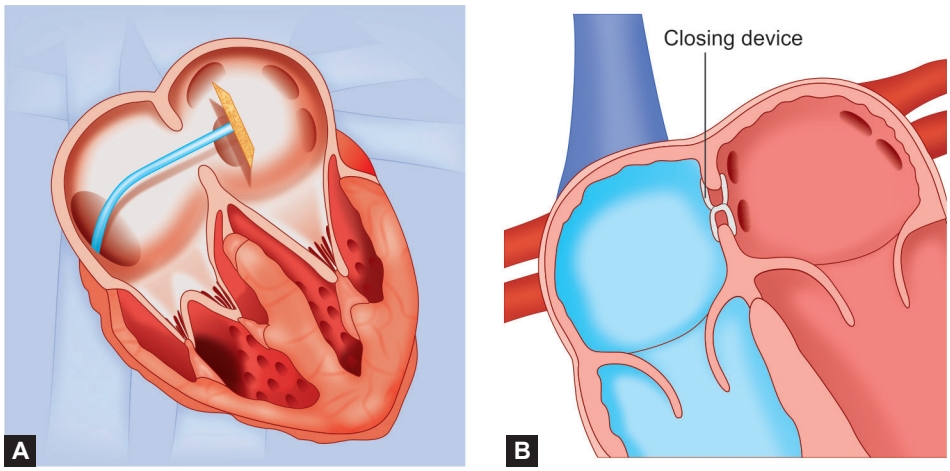
No, bathing does not cause pneumonia. However, babies should be dried thoroughly and kept warm after a bath. In fact, if a baby is not bathed regularly, your baby's skin will get covered with "bad bacteria" which actually can cause serious infections including infection in the heart.

Q4

My baby has been advised a nonsurgical or catheter procedure for a heart defect. What is this procedure?

- Many defects can be corrected by a catheterization procedure or non-surgical procedure.
- A nonsurgical or catheterization procedure is done by a pediatric cardiologist. *A long and thin tube called a catheter is inserted into the blood vessels usually from the groin and guided into the heart under the guidance of fluoroscopy (X-ray imaging).*
- This catheter today is used to close simple defects, e.g., holes in the heart such as ASD, VSD, or other defects such as PDA by loading a device at the end of the catheter. A tight or a narrow valve can be opened by a balloon loaded at the end of the catheter. This is often called "ballooning".
- This "catheter" is also used for making accurate diagnosis and to measure pressures within the heart in more complex situations, to confirm if your child is operable, and to provide more specific and detailed information to the surgeon.
- The most common nonsurgical procedure is closure of an ASD or atrial septal defect—a hole in the atrial septum, i.e., the wall between the two small upper chambers in the heart.

*A diagrammatic explanation of an ASD or atrial septal defect device or nonsurgical closure is shown in **Figures 1A and B**. Other procedures are very similar in principle.*



Figs. 1A and B: A diagrammatic presentation of an atrial septal defect (ASD) device or nonsurgical closure.

Q5

My baby has been advised a nonsurgical procedure for a heart defect. What should I expect and what should I do for aftercare?

Amazingly, in majority of cases these are short stay procedures (2–4 days). Your child will be admitted either the evening before or in the morning of the procedure. Your child will be given medicines for pain both during and after the procedure. All children will get light sedation during the procedure and will wake up soon after without having any frightening memories. In some cases, full anesthesia may need to be given, if the cardiologist considers suitable.

Catheterization procedure is done under fluoroscopy guidance, i.e., there will be some exposure to radiation. However, all doctors take precautions to ensure that your child is exposed to only a minimum amount and duration of radiation.

There are no scars with these procedures—only a small puncture in the groin. Most often your baby or child will be stable at discharge and *as nearly normal as possible*. Your baby can and should be bathed the next day. Feeds and diet is usually normal. If liquid intake has to be reduced you will be told by the cardiologist. Likewise, the need for follow-up check will also be told by your cardiologist. Most often, no medicines are needed; if any are needed, then you will be advised.

Post-intracardiac device implantation, your child would be advised to take tab Aspirin (blood thinner) for a period of 6 months.

Q6

My baby has been advised heart surgery. What does this involve?

The most common heart surgery is for holes in the heart that are too large to be closed by a device or catheterization procedure. These holes are stitched by the surgeon using various materials. The heart has to be stopped and opened for this to be done. *Your child's circulation and breathing will be artificially supported by a heart lung machine and your child will be under full and deep anesthesia.*

Your child will neither feel pain nor have any frightening memories. Unfortunately, there will be a surgical scar which may be more prominent in some children. Today even one day old babies can safely undergo heart surgery depending on the nature and complexity of the heart defect.

*Some pictures of heart surgery are shown in **Figures 2 and 3**. The incision or the cut is usually on the chest in front as shown here.*

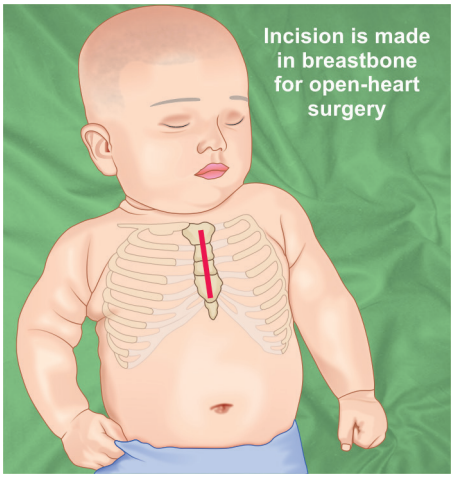


Fig. 2: *Heart surgery:* The incision or the cut is usually on the chest in front.

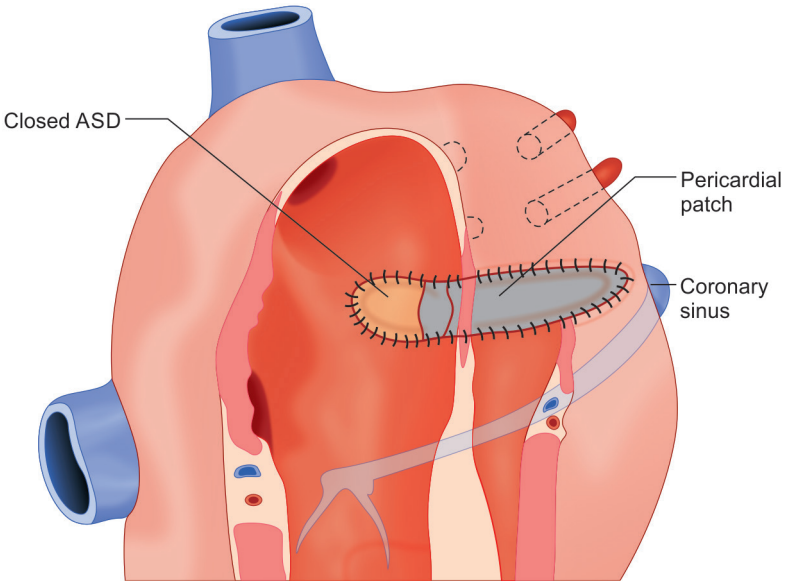
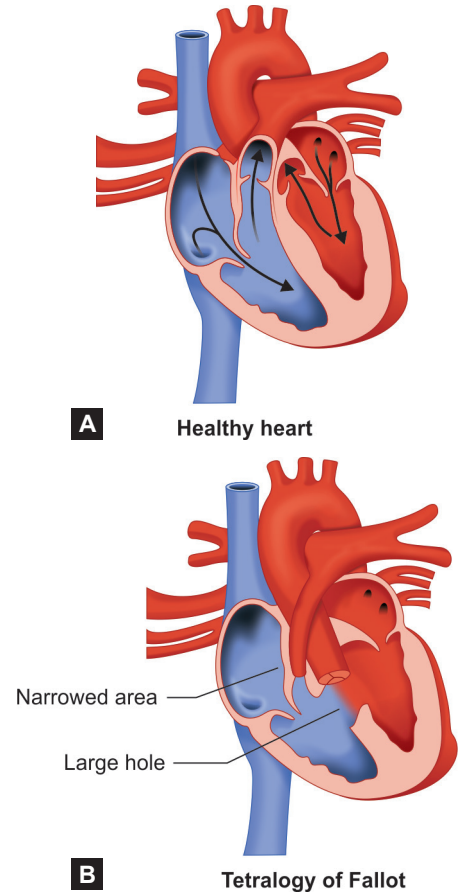


Fig. 3: Holes closed with patches and suture or stitch lines shown within the heart.

Surgery for tetralogy of Fallot involves closing the large hole as well as opening up narrowed valve and nearby areas ***(Figs. 4 and 5)***.



Figs. 4A and B: Surgery for tetralogy of Fallot involves closing the large hole as well as opening up narrowed valve and nearby areas.

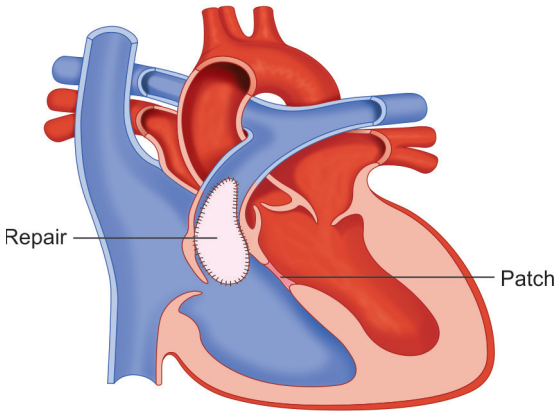


Fig. 5: Surgery for tetralogy of Fallot involves closing the large hole as well as opening up narrowed valve and nearby areas sometimes with a patch.

Q7

My baby has undergone heart surgery. How should I look after my baby?

Heart surgery is a frightening experience for any parent. Fortunately, with progress in surgical techniques most infants and children have a smooth postoperative course in the hands of a competent surgeon.

Aftercare involves treating your baby or child as normally as possible. The final goal is mainstream integration of your child. *Children return to normal activities within a few days after surgery and may be permitted to go to school after 6–8 weeks with prior clearance from the treating cardiologist* ***(Fig. 6)****. Most patients will be advised medications for a few weeks to allow the circulation to adjust after surgery and some may require long-term medication, if some artificial material has been used.*

All repaired hearts are not the same, and some are weaker than others and will need lifelong follow-up and some may need future repeat surgery or nonsurgical interventions such as ballooning or stent.

Fig. 6: Most babies and children after heart surgery are playful and resume normal activity very quickly.

Q8

What about feeding, vaccination, and bathing?

- All breastfed babies should be breastfed as usual. Kangaroo maternal care (KMC) hastens recovery and assures better weight gain and growth.
- Those infants and children with weak hearts will be advised a fluid restricted diet.
- All children can be normally vaccinated 3–6 weeks after heart surgery. Those without a spleen need pneumococcal vaccine in addition.
- All can be bathed normally with soap and water. The wound should also be washed carefully to prevent bacteria entering the wound. Your doctor will tell you, if your child needs to be bathed with chlorhexidine solution.

Q9

What about physical activity and schooling?

Most infants and children find their level of comfort regarding physical activity **(Figs. 7A and B)**. So, infants do not need to be stopped when they walk, run around, or play. In older children, combative sports, PT, i.e., physical training, gym, swimming, and karate should only be allowed after speaking with the cardiologist. In general, a low level of regular exercise is both useful and beneficial for most children after heart surgery including complex single ventricle surgeries as per recent published literature.

All infants and children are encouraged to attend school unless they have in addition special needs—then they need to attend special schools which address their other needs. *Some schools may ask for a fitness certificate from the doctor. Your cardiologist will be happy to give you one. It is important that the school authorities are aware that your child has had heart surgery and this information should not be withheld from the school authorities.*

Figs. 7A and B: Many children after nonsurgical or surgical procedures of the heart are able to resume an amazing level of physical activity.

Q10

What about choice of profession, marriage, and child bearing since my child has undergone heart surgery?

Other than armed forces and a career pilot, most professional courses and professions are open to those who have undergone heart surgery. Many become doctors, engineers, lawyers, and other professionals.

It is wise to discuss the heart surgery openly with your child's future partner and many marry after heart surgery. Only those with *profound heart failure and with a large heart* may find marriage difficult since they get breathless with even mild activity.

Likewise, many women who have undergone multiple surgeries or valve replacements have been able to undergo pregnancies uneventfully and have gone on to have happy families.

However, it is a good idea to discuss choice of profession, marriage, and childbearing beforehand with your cardiologist, and particularly your heart surgeon who has actually seen your heart on the operating table.