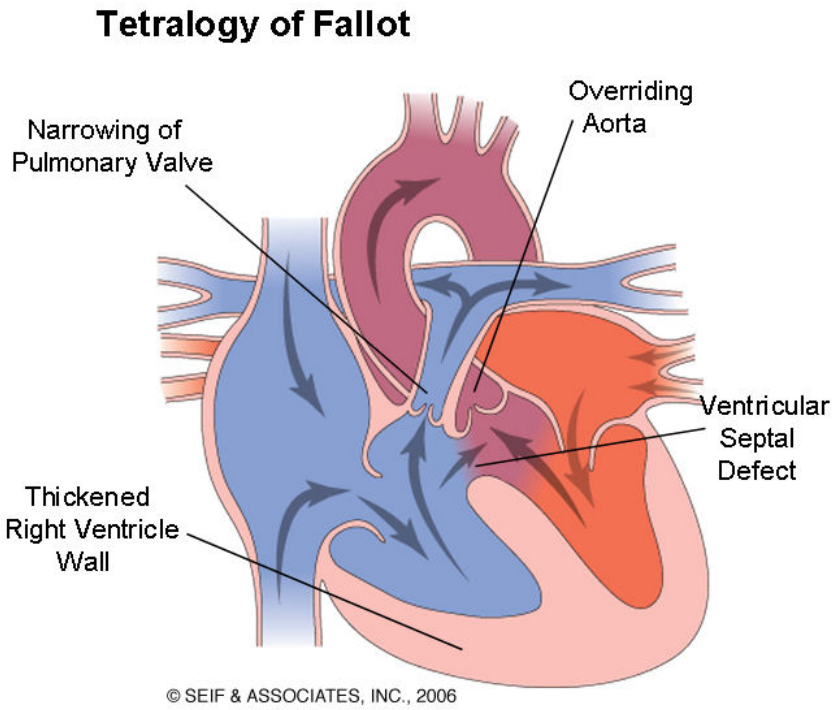
Tetralogy of Fallot, Living With

With new advances in testing and treatment, most children who have Tetralogy of Fallot repaired with surgery survive to a healthy adulthood.

FOR PARENTS



- Parents of children born with Tetralogy of Fallot often think that they did something to cause the problem. It is important that parents know that they did not cause their child's illness.
- It is important that you keep your health insurance current. If you think about changing jobs, check to see if the health insurance at the new job will cover a child who has Tetralogy of Fallot.
- It is also very important for your child to have health insurance as adulthood approaches. Review your current health insurance plan. Find out how coverage can be extended beyond age 18. Some policies may allow you to keep your child on your plan if he or she remains in school or is disabled.
- The care and treatment of a child with a complex congenital heart condition like Tetralogy of Fallot can be very stressful for families. This is especially true during the period surrounding the surgery. Support is very important. Talk to your caregiver or hospital social worker about a parental support group in the area. In these groups, you can talk with other parents who are going through the same thing. Counseling can also be very helpful.

GENERAL ISSUES

It is important for your child to have regular medical care. This includes:

- Followup with your child's pediatrician or family doctor for regular exams.
- Lifetime followup with a heart specialist.
- It is important for anyone with Tetralogy of Fallot to have routine dental care to prevent tooth decay. This can lead to infections in the heart. Throughout your child's life, he or she should take antibiotics before any dental procedure, including cleaning. Talk to your doctor before taking your child to the dentist.
- You may consider having your child wear a medical alert bracelet or necklace. This tells anyone caring for your child that the child has a congenital heart condition.
- Some children and adults with Tetralogy of Fallot may need to limit certain types of exercise. The limits vary with each child. Discuss with your child's doctor:
  - Whether your child needs to restrict activity or exercise.
  - Whether your child can play in organized sports, especially contact sports.
  - The need for a note for the school or coaches about limiting your child's exercise.

REGULAR TESTING IS USUALLY RECOMMENDED:

- A Holter monitor may be recommended. The Holter monitor is a small box that is usually worn for a 24-hour period. The Holter monitor provides a continuous recording of heart rhythm during normal activity.
- An echocardiogram is a test which uses sound waves to show the heart as it pumps and relaxes.
- Exercise stress test may be recommended. Some heart problems are easier to diagnose when the heart is working hard and beating fast. During stress testing, a patient exercises or is given medicine to make the

heart work harder and beat fast while heart tests are performed. During exercise stress testing, blood pressure and EKG readings are monitored while the patient runs on a treadmill or pedals a bicycle.
- In addition to an EKG, other heart tests, such as nuclear heart scanning or echocardiography, can also be done.

SPECIAL NEEDS FOR CHILDREN

Your pediatrician or family doctor checks your child for growth and development at each routine checkup. Some children with Tetralogy of Fallot do not grow and develop as fast as other children the same age. Most children "catch up" after surgery.

SPECIAL NEEDS FOR TEENAGERS

- Help your teenager cope with the stresses of growing up with a health problem. Remind your teenager that, with proper care, he or she can grow up healthy and participate in most, if not all, activities.
- Let your teenager help make decisions about medical care and his or her life. This fosters independence and encourages regular followup with the doctor.
- Some teenagers or young adults need additional surgery. The cardiologist will discuss with you and your teenager the need for any additional heart surgeries.

SPECIAL NEEDS FOR ADULTS

- Over time, some adults may need medicines to help improve heart function or to help stop irregular heartbeats. A cardiologist can decide if you need any medicines. It is important to check with your doctor before changing or stopping any medicines.
- Just like teenagers, some adults need additional surgery. Other people with Tetralogy of Fallot may need to have a pacemaker or defibrillator to help stop or control irregular heartbeats. Your cardiologist will discuss with you the need for any additional surgeries.
- Adults who were born with Tetralogy of Fallot should consider job changes very carefully, because health benefits may change. Some health plans have waiting periods or clauses to exclude some kinds of coverage. Before making any job changes, find out if the change will affect your health insurance.

PREGNANCY AND TETRALOGY OF FALLOT

Women with Tetralogy of Fallot who want to become pregnant (or who are pregnant) need to:
- Talk to their caregiver about health risks during pregnancy.
- Talk to their caregivers about medicines that can be taken during pregnancy.
- Consult with specialists who take care of pregnant women with health conditions.
- Talk to their caregivers about any new or worsening symptoms.

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