My Child Needs or Has an Implantable Cardioverter-Defibrillator

What Should I Do?

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The identification of a heart problem in a child can create fear and uncertainty for parents. This patient page will address some common questions from parents of school-age children who require therapy with an implantable cardioverter-defibrillator (ICD). It is intended to be a parental resource to promote understanding and confidence in children and young adults to live successfully with an ICD.

Understanding ICDs

What Is an ICD?

An ICD is not a cure, but instead can be viewed as an insurance policy, protecting at-risk individuals against dangerous heart rhythms. Previous research has indicated that ICDs significantly reduce the risk of sudden cardiac arrest in patients at risk for sudden cardiac death.1 An ICD is a small implanted device that monitors the heart rhythm and is able to stop a dangerous heart rhythm that could result in sudden cardiac death by either rapidly pacing or shocking the heart back to a normal rhythm. Open-heart surgery is not required to implant the device. The ICD is typically placed in the upper left chest and has sensing wires that attach to the walls of the heart muscle. Your child will likely have the ICD throughout his or her lifetime and will need the battery changed every 5 to 7 years. It will require monitoring by a cardiologist, typically every 3 to 6 months, which can be done painlessly with a monitoring system from home or in the cardiologist’s office.

My Child Needs an ICD

What Questions Should I Ask?

At first, it may feel like you have so many questions that you don’t know where to start. The Table details a number of key questions and answers. In addition, here are some important things you may want to ask your child’s cardiologist:

- What is my child’s diagnosis, and what implications does this carry?
- Should I consider genetic testing to determine whether other members of my family are at risk for sudden cardiac death?
- Where will my child’s device be placed, and what will it look like?
- What will my child’s activity level be like immediately after implantation and in the future?
- What medications will my child need? What about cost, dose, and side effects?
- Does my insurance cover the procedural costs/medications?
- What safety precautions/activity restrictions are recommended once my child is home with the device?

How Do I Deal With My Emotions?

As a parent, you may feel frustrated, angry, disappointed, or that you lack...
control. No parent ever wants to hear that a son or daughter has a heart condition or is at risk for sudden cardiac death. One helpful approach is to view (and help your child understand) the ICD as protection or an insurance policy to live more confidently. With the ICD, the child is protected in the best way medical science has to offer. Your child may benefit from focusing on a survivorship mentality that emphasizes being committed to living long and well, regardless of the occasional medical intrusions. A strong community of family or friends can support this approach. If anxiety, excessive worry, depression, or emotional distress becomes a problem, mental health professionals are prepared to offer support and guidance.

Table. Children’s Frequently Asked Questions and Answers

<table>
<thead>
<tr>
<th>Question</th>
<th>Answer</th>
</tr>
</thead>
<tbody>
<tr>
<td>Why do I have an ICD?</td>
<td>Your heart could go into a dangerous rhythm that could cause you to die. Your ICD will protect you if that happens.</td>
</tr>
<tr>
<td>What will I look and feel like?</td>
<td>You will have a very small scar on your chest and perhaps a small bulge under your skin. After it heals, it will be comfortable and not bother you.</td>
</tr>
<tr>
<td>What does a shock feel like?</td>
<td>A shock feels like a quick kick in the chest (6/10 on the pain scale with 0=no pain, 10=worst pain). It lasts less than a second, and then it’s over. It is more surprising than scary.</td>
</tr>
<tr>
<td>When could it shock me?</td>
<td>It could shock you any time you have an abnormal heart rhythm. The timing of arrhythmias is difficult to predict.</td>
</tr>
<tr>
<td>Can I play sports?</td>
<td>Many people with ICDs can be very active, but contact sports have generally not been recommended. Let’s talk to your provider about the possibilities.</td>
</tr>
<tr>
<td>What restrictions are there?</td>
<td>Restrictions include some contact sports, roller coasters, magnetic resonance imaging tests, and welding. However, there are plenty of activities that you can do, and we can talk about these.</td>
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<tr>
<td>How long will I have to take medicine?</td>
<td>You will most likely have to take medicine for the rest of your life because it helps your heart to stay in a normal rhythm.</td>
</tr>
<tr>
<td>What if the medicine makes me tired or sad?</td>
<td>The medicine is very important to help you stay healthy and not have a problem with your heart condition, which would require a shock. Your body will adjust to it in time. We have to balance the good it does with its side effects.</td>
</tr>
<tr>
<td>How do I remember to take my medicine every day?</td>
<td>Use a weekly pill box, and remember to take it at the same time every day, like when you brush your teeth at night.</td>
</tr>
<tr>
<td>Will I have this ICD for the rest of my life?</td>
<td>Probably. Because we do not know when or if you will need the ICD to terminate an arrhythmia, most ICD patients continue to have an ICD.</td>
</tr>
<tr>
<td>What will other kids think?</td>
<td>They probably won’t notice unless you tell them. Once you tell them what it is, other kids usually think it’s cool.</td>
</tr>
<tr>
<td>Will I ever need a new one?</td>
<td>You will probably get a new device or battery every 5 to 7 years.</td>
</tr>
<tr>
<td>Am I the only kid with an ICD?</td>
<td>No! Perhaps we can meet other people with ICDs at a local support group. Absolutely. Yes!</td>
</tr>
<tr>
<td>Should I tell coaches and teachers?</td>
<td>You should be careful not to become dehydrated, and tell the doctor when you have diarrhea or vomiting.</td>
</tr>
<tr>
<td>Can I buy a cool medical alert bracelet?</td>
<td>Arrhythmias are potentially dangerous, and that is why you have an ICD. The purpose of the ICD is to keep you safe. The ICD is like a lifeguard at the pool to watch your heart for any signs of trouble and protect you.</td>
</tr>
<tr>
<td>Can I eat and drink what I want to?</td>
<td>It’s a funky heart rhythm.</td>
</tr>
</tbody>
</table>

ICD indicates implantable cardioverter-defibrillator.

My Child Has an ICD

How Might an ICD Change My Child’s Quality of Life?

Young ICD patients are adaptive and often courageous. Although an ICD can undoubtedly save a life, living with one can be challenging. Parents who find their children withdrawing from their favorite activities or interests can help by encouraging the child’s participation and discouraging avoidance. Parents often believe that their children have a lower quality of life than their children actually report. Keeping an open dialogue with your child about his or her reaction to having an ICD will help your child to feel understood and heard while keeping you informed about your child’s ability to cope with new or ongoing stressors. Research has also shown that females can experience unique challenges related to social role maintenance, femininity, sexuality, and caretaking abilities.

What Should I Watch for?

The way your child deals with stress depends on age and developmental level, temperament, and family situation. Anxiety is the most common psychological symptom experienced...
by ICD recipients, and therefore they may experience a greater need for affirmation from friends and family.5

**When Should I Involve a Mental Health Professional?**

Signs that a youngster is having difficulties adjusting include school absences, social isolation, or avoidance behaviors. Family and counseling therapy can be helpful for patients and their loved ones when coping difficulties are observed.3

**What Are Some Developmental Concerns Associated With Having an ICD as a Child?**

As a parent, you may struggle with how to discuss the ICD with your child. Information provided to children should be tailored to their maturity level, health literacy, needs, and readiness to understand their cardiac condition. Children often exhibit an increased readiness to learn at key points in development. Watch for teachable moments, and provide education and counseling at your child’s maturity level. Children can be encouraged to take an active role in managing their condition by participating in taking medication and interacting with their pediatric cardiologist at appointments. As children mature, they should become progressively more independent and informed about managing their medications, medical visits, and any necessary lifestyle modifications. In middle to late adolescence, conversations about vocations and careers, pregnancy, and long-term goals are appropriate and helpful to empower children to manage their own health. Finally, the transition to an adult cardiologist should be a gradual process that involves the child, parents, and pediatrician. It is during middle to late adolescence that many pediatric patients move to adult cardiologists but also have the most difficulty adhering to medication.4

**What About Medications?**

Be aware that common medications may change heart rhythm. Make sure that all of your child’s healthcare providers are aware of the cardiac condition and any contraindicated medications. Many children will be prescribed medications such as β-blockers to lower the chances for arrhythmia and therefore decrease the chance of a shock from the ICD. These medications may cause fatigue until your child gets used to the medication; however, they are imperative to the child’s treatment plan.6 Taking the medication at night before bed can help with these side effects, and the child will adjust to a normal energy level over time. Avoiding dehydration is also important because this can precipitate arrhythmias. Therefore, it is important to keep in close contact with your pediatrician if your child is experiencing vomiting or diarrhea. Empowering your child to manage these issues without being fearful or overprotective but while still being watchful is a balance for which parents should strive.

**How to Respond to ICD Shock**

The experience of ICD shock is the most unique aspect of living with an ICD. Shock is used to terminate a potentially dangerous heart rhythm and is generally described as discomforting and unpleasant. However, if you are touching your child during a shock, you will not be hurt. Successful planning, management, and response to an ICD shock will allow each member of the family to be prepared and respond optimally. Figure 1 illustrates a typical shock plan for you to discuss with your physician and family in the event of a shock.7

**How to Teach and Support My Child**

**What Can I Do?**

Your child will adapt to life with an ICD and cope with the anticipation of an arrhythmia or shock. It is expected that he or she will experience some level of emotional stress, and it is important to provide open, honest, and age-appropriate information to provide the tools for adaptation. You can provide your child with a sense of safety by keeping your home life as consistent as possible. Parental withdrawal can cause the child feelings of insecurity and guilt. Don’t be afraid to express your feelings of sadness or worry to your child. Treat your child as normally as possible within the limitations of his or her illness.5

Teachers, coaches, relatives, and friends are your child’s community and also play an important role in your child’s sense of security and safety.
Each functions as an important advocate. They should receive the same information as that provided to your child. A child-friendly medical alert bracelet can offer both child and parent peace of mind and contact information in case of emergency. Figure 2 depicts actions for parents across 3 situations.

How Can We Boost My Child’s Self-Esteem?

No matter what the age, a fun way to develop comfort with this new device is to give it a name. Calling the device by a name may make it easier for the child to express feelings and concerns about it. For example, ICD names such as Luke Skywalker, Mr Lifeguard, Sparky, or The Rock denote a sense of protection and safety. This represents another effort to accept the ICD as part of the child’s life. T-shirts are available that share a lighthearted and empowering approach to heart disease and ICDs.8

Conclusion

This patient page reviews key aspects of helping families to live with heart disease and ICDs. A working knowledge of the value and importance of the ICD, a shock plan, and ongoing support of your child allow families to adjust well over time and experience a sense of security from cardiac threats. The eventual acceptance and confidence of living life fully with a cardiac condition and an ICD can become part of the ultimate cardiac comeback story for you and your child.

Appendix

About the Dimsdales

Carolina (Callie) and Allison Dimsdale have specific knowledge and experience on this topic. Callie, now 25 years of age, is the daughter of Allison and Todd Dimsdale. At 18 years of age, she was diagnosed with long QT syndrome, and an ICD was implanted. As a Cardiovascular Nurse Practitioner, Allison has both professional and personal insights into the challenges that mothers and daughters face in the identification of pediatric cardiac problems and decision making related to ICD implantation. This article is enlightened directly by their previous needs and experiences in this situation. Callie is now a registered nurse at Duke Hospital’s Cardiac Intensive Care Unit. They both will graduate this summer from Duke University, Callie with a Master of Science in Nursing (MSN), and Allison with a Doctor of Nursing Practice (DNP).

Disclosures

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References

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