



## Heart Smart Guide for Young Patients With Cardiac Devices

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Learning that you have a heart condition can be scary and confusing. The purpose of this patient page is to answer questions you may have about how to confidently manage your condition and your new device. Strategies to help you stay healthy, deal with stress, and return to school and other activities can help you feel more confident. Learning about what to do in different social situations can help you prepare to talk to friends and other people in your life about your device. If you do not find all your answers here, keep asking questions and engage your loved ones in the process. Your cardiac care team can help, along with other key people in your life.

### Get Heart Smart

The first step in getting used to life with a cardiac device is to get heart smart! Learning about your cardiac disease and your device can go a long way, especially when it comes to improving your confidence. The best way to start this process is to learn about your device and why your care team decided you needed one. Cardiac devices are

implanted for a couple of reasons. Devices can be used to stop dangerous heartbeats with a shock or add heartbeats when they are missing or slow. They can also be used to pace a heart out of a dangerous heartbeat (arrhythmia) with small electric signals.

If you have a pacemaker, you can feel comfortable knowing that your pacemaker will do its job automatically. If you have an implantable cardioverter defibrillator (ICD), it will also do its job automatically, but you will also want to know what to do if it provides a shock. Another patient page, *My Child Needs or Has an ICD: What Should I Do?* has even more information about making a shock plan.<sup>1</sup> Having a shock plan is like having a fire drill at school. Being prepared for a cardiac event can relieve a lot of worry.

Understanding your medications can also help you feel confident. Medications give your heart help to do its job easily. Learn what your medications are and why you take them. Your cardiac care team is there to answer the questions you ask. Taking your medications on time and the exact way your

care team tells you helps you and your heart. Your cardiac device is the second line of protection. Your device is a safety net to catch arrhythmias that your medication does not fix. We know that if you do not like the way your cardiac medications make you feel, you are less likely to take them regularly. Let your cardiac care team know about any side effects from the medications that you do not like. Sometimes small adjustments in the medications can make a big difference.

### Manage Device Stress

Cardiac patients may be at risk for having difficulty with worry and sadness. If you are worried about your device, you may need to spend more time getting heart smart and learning about your condition and device. Just as going to school prepares you for a job, learning about your cardiac health will help you take charge of your health. The more you know, the fewer worries you will have.

If you are feeling down or sad because of your heart or device, tell someone. Whether you tell a friend,

The information contained in this *Circulation* Cardiology Patient Page is not a substitute for medical advice, and the American Heart Association recommends consultation with your doctor or healthcare professional.

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## Cardiac Devices: A Primer for the Family, Friends & Support Team

### Who needs a cardiac device and what do they do?

- People at risk for too slow, too fast, or irregular heartbeats (arrhythmias).
- Devices can be used to pace or interrupt irregular heartbeats into rhythm.
- *Pacemakers* send small, electrical signals to pace the heart out of the arrhythmia.
- *Implantable cardioverter defibrillators (ICDs)* use both low and high electrical energies (shocks) to terminate dangerous arrhythmias.

### What is an ICD shock? Can the shock affect me?

- An ICD shock occurs when the device senses a continuing arrhythmia.
- The device gives the heart time to correct itself, but if the heart is still in danger, the device will fire.
- Shock is delivered to terminate the dangerous heartbeat and restore a normal heart rhythm.

### What should I do if their ICD fires?

- It is important to have a shock plan.
- Shock plans are similar to fire drills, we hope to never experience a dangerous situation, but if we do, there is a plan in place.
- For an example of a shock plan see: <http://circ.ahajournals.org/content/126/16/e244.full>

### Is it okay to talk about their heart and device?

- Yes. Chances are, someone is giving you this handout to help you better understand their health and cardiac device.
- Talking about their cardiac health may help with adjustment to the device.
- Talking about the device does not put the individual at risk for developing psychological distress; in fact, it may help reduce distress.

### What if I notice they seem sad or worried?

- Encourage them to keep learning more about their device and cardiac condition. Knowledge can help manage distress.
- Let them know that you are available to talk.
- The cardiac care team and school providers might have suggestions to help manage their feelings.
- It is normal to experience worry and sadness while adjusting to a cardiac device, just like other life changes.

### Is activity safe for a person with a cardiac device?

- In most cases, yes. After the device is implanted, the doctor will give activity restriction (usually 6 weeks).
- Returning to a normal routine will help decrease distress that could result after device implantation. A member of their care team should be able to identify any activity restrictions.
- In most cases, returning to sports, recess, physical education class, and having fun is good for the heart and will not hurt the device. Medical clearance should be obtained.

### School Strategies

- Plan ahead and communicate frequently about classwork.
- Tutoring at school, home, or hospital may be an option.
- Help identify new strategies for academic success.
- Consider educational/psychological evaluation if appropriate.
- The student may be eligible for additional services and supports in the school setting.

Figure. Cardiac devices: a primer for the family, friends, and support team.

**Table 1. Checklist for Returning to Activity and Managing Distress**

Remind yourself that you are safe.

- The purpose of your device and your medical team is to put a safety net in place so that you can become the person that you want to be.

Set goals for your return to activities.

- Review the activities that you have enjoyed in the past.
- Discuss a plan of return with your doctor, family, and friends.

Return to activity with approval.

- Reengaging in activities can be unsettling at first. Your medical team and family are important sources of reassurance that it is ok to be anxious as you take steps on making a comeback.
- Ask your doctor about how to modify your favorite activities at first before full return.
- Identify small victories or steps to return and celebrate them!

Ask for help from your support team.

- Family, friends, and medical team members all want to see you get back to normal.
- Give them a chance to encourage you or help you in your process of return.
- Thank your support team for their help.

sibling, parent, or a doctor, people want to know how you are feeling. Your cardiac care team might have suggestions to help manage your feelings. They may also be able to refer you to a counselor or cardiac psychologist for some booster sessions, while you adjust to your device. Your feelings are connected to your behaviors.

A good strategy for managing your feelings is taking care of yourself; this is called self-care. Self-care includes (1) eating a healthy diet, (2) getting regular physical activity, (3) spending time with family and friends, and (4) doing other activities you enjoy. This is a simple checklist you can use to remember the key ingredients to self-care. Do not be surprised if you experience worry or sadness while managing your health; we all need a tune-up every once in a while.

### Relationships

Sometimes stress goes along with having a cardiac condition and device. Keeping strong relationships and building new ones can help you deal with stress. Relationships can be valuable because they give you people to talk to and help you handle stress. Sometimes relationships can be tricky to handle. You may feel confused or embarrassed about telling other people about your device. You may find that some people, like your parents, treat you differently now that you have a

device. The best way to handle all of your relationships is to communicate. Let your parents and other people know how you feel. Feelings of sadness, worry, and stress are common in patients who have a cardiac device, and your support system may be able to help you adjust. If you have a question about your device, you should ask your doctor or someone else on your cardiac care team. Your doctors are there to help you and can be a great source of information!

Take charge of your health! A strategy to strengthen relationships is to have open and honest conversations about your condition and device. When others do not know about your device, you have the chance to be the expert and explain your device to them. You should only share as much as you are comfortable sharing. It can be helpful for some people to know about your device (Figure). For example, letting your teachers know about your device can be helpful if you have an ICD shock or if you have to miss school for doctors' appointments.

### Activities

Returning to activities may be one of the biggest challenges that young people with cardiac devices face. After you have healed from surgery and your doctor has cleared you to

be active, the best thing you can do is get back to doing the things that you enjoy! Research with children with ICDs has indicated that as many as 84% of kids avoid activities regularly.<sup>2</sup> Some heart conditions may limit your activity. Check with your doctor to see if your activity should be limited. In most cases, you can go back to playing many sports, going to recess, participating in physical education class, and having fun! Physical activity is good for your heart and will not hurt you or your device. Table 1 details a set of steps that might help get you back to some of your favorite activities.

### School

Just like some of the other situations we have discussed, the best way to handle things going on at school is to communicate! A strategy for communicating with your school is to stay in contact with your teachers about absences, home assignments, and any challenges you face at school. Your school will probably want a doctor's note to say why you have missed or will miss school for appointments with your cardiac team. Talking to your teachers, staff, school psychologist, counselor, nurse, and other important people at school about what is going on with you will help them support you as you catch up



**Table 2. Steps Toward Confidence With Your Cardiac Device**

Steps	Questions	Plan
Step 1 Get heart smart!	Why do I have a cardiac device?	You have a cardiac device to keep your heart rhythm normal. A cardiac device was implanted to help identify and interrupt irregular heartbeats, or send small electric signals to pace your heartbeats.
	Why do I take medications?	Ask questions! Your cardiac care team is on your team and can help with managing your medications and teaching you their purpose.
	What if my medications make me feel weird?	Talk with your doctor, he or she should be able to help you figure out what medications are making you feel weird or not like yourself and explain why or adjust the dosages to improve your symptoms.
	What do I do if I get shocked?	Know your shock plan (if you have an ICD).
Step 2 Manage device stress	What if I am worried about my heart?	Get heart smart. Learn as much as you can about your device and condition. An educated patient is a confident patient. Remind yourself that you have a plan to reduce risks with your medical team, your medications, and your device. Plans help keep you safe.
	What if I am feeling down or sad because of my heart or device?	Talk with your doctor about your concerns, he or she may have suggestions for you or be able to refer you to a counselor, school counselor, or cardiac psychologist.
	Sometimes I feel self-conscious about my scar and try to hide it from others, especially in social situations (ie, changing clothes for gym class). What should I do in those situations?	Scars prove healing. The way patients feel about their scars can vary from person to person and change over time. It may be helpful to think of your scar as a badge of strength and a reminder that you are healthy and have a good care team. Talk to your school counselor, parents, or your doctor about your concerns.
Step 3 Build strong relationships	What if I feel like my parents are too worried about me now that I have a device?	Talk to them! It's important that you tell your parents how you feel so you can work together to make a plan to help you and your parents feel better.
	What if I have a question about my device?	Ask! Your doctors and nurses can always answer questions. Each device company has phone numbers and websites that will answer specific questions.
	Should I tell my teachers about my device?	Great idea! Letting teachers know about your device can help them to help you if you need to miss school. If you have an ICD, it is a good idea to share your shock plan with your teachers so they can help in case of a shock. Your school nurse can help make sure everyone has this information.
	How do I tell my friends or boy/girlfriend about my device?	Be the expert! It's a good idea to let friends know about your device. Share as much or as little as you want. If you have an ICD, share your shock plan with friends so they can help if you need them.
Step 4 Return to activity	What if I do not have anyone to talk to?	Everyone needs to have someone they can talk to. If you need help finding a professional, ask your medical team about possible referrals to healthcare providers in your area.
	Why should I return to activity?	The qualities of life are often tied to recognizing and doing what you enjoy. Activities are part of that and achieving a high quality of life is a goal that brings most people a level of happiness or contentment.
	Can I play sports? Can I participate in PE?	Yes! Most sports are considered safe for you and your device. Contact sports are generally not encouraged, but each situation should be discussed with your doctor. In most cases, physical activity is a great idea! It will not hurt your heart or your device.
Step 5 Manage school concerns	How do I catch up after missing school?	You and your parents can talk with people at school to set up a plan for completing missed work and getting back on track with your classes. You might feel overwhelmed, but engage others to support you and help you make a successful transition back to school.
	I know that I will be missing school, is there anything I can do ahead of time so I don't fall behind?	Some options may include getting your assignments ahead of time from your teachers, using electronic communication while you are out, or using home-bound tutoring. Home-bound tutoring is when a student or teacher can come to you and help explain what is being taught in your classroom.
	What if things do not go back to normal once I'm back in school?	If classes seem more difficult, or you have trouble paying attention, bring those things to the attention of your teachers and parents. They can help!
	I have heard that I might have to do extra testing at school, what is that about?	Sometimes people at school might need information about how you are feeling after you get your device. This information can help your care team make a plan to support you. One way to do this is to have you complete an educational and psychological evaluation.
	What about college?	It is great that you are thinking ahead to college. Just like dealing with missed work, the more you talk to your teachers and school staff about your grades and future plans, the more prepared you will be.

ICD indicates implantable cardioverter defibrillator; and PE, physical education.



and get used to being back. If class-work seems harder or things that used to come easily to you are more difficult, it is ok. It may just mean that you need some new strategies to help you be successful in your classroom. There are plenty of people at your school that can help!

### Conclusion

Now that you have read through the steps to device living for young patients with a cardiac device, take a step back and see which of these steps may need more attention for

you. Keeping these steps and simple strategies in mind will also help manage your stress (Table 2). If you have a plan for managing your medical care, device stress, relationships, activity, and school concerns, you can use what you know to put your plan into action. Your medical care team wants to see you succeed and return to the places and activities you enjoy.

### Disclosures

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