

Name: _____

ICD name and model number: _____

ICD serial number: _____

Atrial lead name and model number: _____

Atrial lead serial number: _____

Ventricular lead name and model number: _____

Ventricular lead serial number: _____

Surgical Date: _____

Who to call for help.

Pediatric Cardiologist: _____

Contact Number: _____

After hours, contact the cardiologist on call at:

Cardiac Surgeon: _____

Contact Number: _____

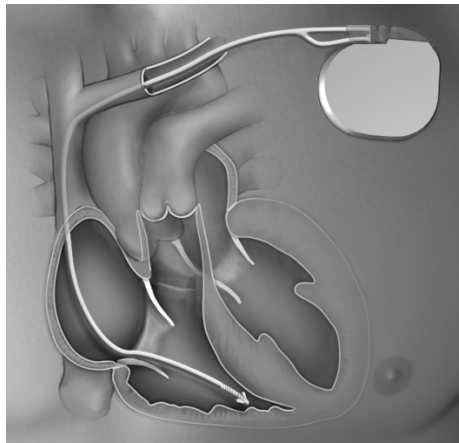
Nurse Clinician: _____

Contact Number: _____

Care of Your Child with an Implantable Cardioverter Defibrillator

Defibrillator

Your child has had an Implantable Cardioverter Defibrillator or ICD inserted to help treat their irregular heart beat. Sometimes this device is called an Automated Implantable Cardioverter Defibrillator or an AICD.



Heart with an Implantable Cardioverter Defibrillator

It is normal to have lots of questions about how the ICD will affect your child. This booklet helps answer those questions. Please be sure to discuss any questions or concerns you may have with your child's health care team.

What is an Implantable Cardioverter Defibrillator (ICD)?

It is an electronic device that gives your child's heart a shock in the event of an irregular heart rhythm (arrhythmia) that is life threatening. Examples of life threatening heart rhythms are ventricular tachycardia (abnormally fast heart rate) or fibrillation (rapid, uncoordinated contraction of the heart muscle). The ICD gives the heart a jolt of electricity to restore the normal heart rhythm. It does not prevent these irregular heart beats from occurring.

The ICD can also act as a pacemaker. It does this by checking the heart's electrical activity and keeping a normal heart rhythm and rate.

GUIDELINES FOR YOUR CHILD'S RECOVERY FROM SURGERY

How do I care for my child's surgical wound?

To place the ICD, surgeons may need to make incisions in your child's chest or abdomen. Your child's nurse will show you how to care for the surgical wounds.

Keep the wounds clean until they are healed. Your child can have a shower as soon as he or she is feeling well enough after surgery.

For 7 days after the surgery, your child should have showers rather than baths to avoid soaking the cuts in water.

When should we come back to visit a doctor?

Your child needs to be seen by a cardiologist within the first few weeks and then on an ongoing basis. It is important to check that the ICD is working as it should and to check its battery.

When can my child return to school?

Your child can return to school when the discomfort from the surgery goes away. This is usually **one week** after surgery. When your child returns to school, he/she should not carry a backpack or heavy books on the side where the ICD was inserted for 6 weeks. After 6 weeks, it is okay for your child to carry a light pack that is worn over both shoulders.

If you have any questions about an activity, or if you are unsure if it is safe for your child to do, discuss it with your child's nurse or cardiologist.

What you can do:

- Tell your child's teachers about your child's ICD and any activity he or she cannot do.
 - Your child should not take part in regular PE classes for 2 weeks.
 - Talk to your child's PE instructors and coaches about your child returning slowly to normal levels of activity, and how they can safely participate in physical activities.
- Give your child's teachers the emergency care plan and explain what to do in case the ICD gives your child's heart a shock. (See instructions in the second part of this brochure.)

What activities should my child avoid in the first 6 weeks after the surgery?

Arm Movements on the Side of the ICD

Your child's ICD is made up of a small, slim, box-shaped device which contains a battery and electronic circuits. It is a mini-computer. The ICD is connected to the heart by one or more wires, called leads. If your child uses the arm or shoulder on the side of the ICD forcefully and repeatedly, these leads could be damaged. If the leads are damaged, there is a small but real chance that the ICD may not work when needed or give your child's heart a shock when it is not necessary.

What you can do:

In the first 6 weeks after surgery:

- Make sure your child brushes his/her hair and teeth with the arm on the opposite side of the ICD.
- Make sure your child rides in a car using a correctly fitting seat belt in the usual position.

TIP: You can buy a padded adaptor for the seatbelt. www.aboutsofttouch.com gives more information.

- Don't let your child swing the arm or shoulder on the side of the body that the ICD is on or repeatedly reach over his/her head with this arm. For example, activities including golf, tennis, bowling, baseball, basketball, volleyball and swimming should be avoided during this time.
- Don't let your child lift weights or objects that are more than 1.5 to 4.5 kg, or 5 to 10 pounds.

When can my child return to regular physical activities and sports?

Your child can return to his or her regular activities **6 weeks after the surgery**. Most sports are fine. Sports in which the ICD is likely to be hit forcefully should be avoided. If the ICD is damaged, it may not work when it is needed. Examples of sports to avoid include: karate, boxing, wrestling and tackle football. Your child may play non-competitive hockey if he/she wears a protective pad over the ICD.

Tip: You can buy clothes and aides, such as Paceguard™, a T-shirt with a protective pad that helps to protect the ICD site. www.paceguard.com gives more information.

Other activities to avoid include bungee jumping and laser tag because the forces experienced in bungee jumping can harm the ICD leads and the magnetic vests used in laser tag can interfere with the functioning of the ICD.

To decide if a sport is okay you also need to think about:

- Your child's age
- Your child's size and the size of their playmates/teammates
- Your child's heart condition.

It is important that your child do sports with someone else. There is an ongoing chance that your child could have an irregular heart rhythm that is life-threatening. Doing a sport on their own is not safe.

What you can do:

- Talk to the cardiologist about your child's sports and activities.
- Tell your child's family and friends that the ICD is fragile. Your child will need another surgery if it is broken.
- Encourage your child to use his or her best judgment when deciding whether or not to take part in an activity.
- Talk to your child about which sports are okay to do and why.
- Talk to your child about the importance of doing any sport with a buddy.

Call for help if...

Call your child's cardiologist or the clinic nurse if your child has any of the following:

- Increased pain, redness, swelling or drainage from the wound

- Edges of surgical wounds coming apart
- Fever above 38°Celsius
- Dizziness, palpitations, “heart racing” that are different from before the ICD was put in
- Fainting
- Chest pain or difficulty breathing
- Beeping or buzzing sensation coming from the ICD

Your child’s ICDs may be programmed to give off sounds or vibrate if it is not functioning correctly.

GUIDELINES FOR LIVING WITH AN ICD

What should I do if the ICD gives my child's heart a shock?

Sometimes a child may receive a shock for a heart rhythm that is not life threatening.

If the ICD gives your child's heart a shock and your child remains conscious, there is no cause for alarm.

- Remain calm.
- Check your child's pulse and assess how he or she feels.
- Call your child's cardiologist. A follow-up appointment will be arranged as needed. Your cardiologist may want to check that the ICD is working properly.

Call for help if...

Call 911 or your local emergency response number if your child:

- Loses consciousness and it is not immediately fixed by an ICD shock. ***Begin CPR if needed.***
- Becomes less alert, drowsy, sluggish or confused
- Receives multiple shocks from the ICD.

What sources of electrical and magnetic charges do I need to be aware of? ¹

Everyday household appliances

Most electrical appliances give off low levels of electromagnetic fields that will not interfere with your child's ICD. Your child can be around most household appliances and tools that are in good repair and are properly grounded, including:

- Microwave ovens
- TVs, AM/FM radios, VCRs, remote controls
- Personal computers, printers, fax machines
- Hand-held appliances such as hair dryers, shavers. (Do not hold these appliances against the ICD.)
- Electric blankets, heating pads

What you can do:

- Keep cell phones at least 15 centimeters or 6 inches away or an adult hands length from the ICD site
- If your child feels "funny" or not right around any electrical equipment, he or she should step away from the area and see if symptoms resolve.

¹ Adapted from "Electromagnetic Compatibility Guide" (Medtronic, 2006) Questions About Electromagnetic Interference (EMI): Living With an ICD (Medtronic, 2003)

Industrial Equipment

There are a few strong sources of electromagnetic fields that could interfere with your child's ICD. To allow your child's ICD to work properly, you should move your child away from:

- Industrial arc welders and furnaces
- Large generators and power plants
- Large magnets, such as those used in some large stereo speakers, vests worn during laser tag and magnetic therapy products
- Antennas used to operate CB or ham radios and other radio transmitters
- Large TV or radio transmitting towers and power lines carrying over 100,000 volts (keep a distance of 25 feet)

Hospitals and medical equipment

Always tell all health care providers that your child has an ICD.

- X-rays and CT scans are ok.
- No Magnetic Resonance Imaging (MRI) tests because of the strong magnets used in this type of test.

Store and airport security systems

Your child should walk through security screening archways, but not stop and/or wait next to the detection equipment.

The ICD may trigger the alarm. Have your child's ICD ID card handy so you can show it. Request a hand search for your child. Ask that the handheld screening tool be held 12 inches away from your child's ICD. The handheld scanner contains a magnet that may temporarily interfere with the ICD.

Can we travel with the ICD?

Yes. Here are some ways you can prepare for traveling and any possible emergencies during your trip:

1. Get travel insurance to ease the high costs of care in other countries.
2. Always carry the ICD device ID card.
3. Be prepared to follow the recommendations for security systems at airports in this brochure. Have your child wear a Medic Alert™ bracelet or necklace. See www.medicalert.ca for more information.
4. Bring enough medicine to last the whole time you will be away from home. Carry it in your hand luggage when travelling.
5. Make an emergency plan and carry it with you and your child at all times.
 - a. Check with your child's cardiologist and/or the website of your child's ICD device manufacturer for Pediatric Electrophysiology support at the places you are traveling to. They often have a listing of doctors around the world that can help you in case of an emergency.
 - b. Ask your child's cardiologist to give you a summary of your child's ICD settings.
 - c. Make a list of your child's medical emergency contact information. Include contact numbers of people in your home area such as a relative or close friend and contact numbers for the places you are traveling to. Keep this information with your child.

More Resources

Heart Rhythm Society Patient Information <http://www.hrsonline.org/PatientInfo/Treatments/ICD/index.cfm>

Medtronic Patient information <http://www.medtronic.com/health-consumers/sudden-cardiac-arrest/device/index.htm>

St Jude Medical Patient information <http://health.sjm.com/arrhythmia-answers/treatment-options/implantable-devices.aspx>

Your Implantable Cardioverter Defibrillator: Patient Manual (Medtronic, 2002)

Electromagnetic Compatibility Guide (Medtronic, 2006)

A Parent's Guide to a Child's Defibrillator (Medtronic, 2004)

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