Giving medications

Your child may need medications (drugs) to manage CHD. Some children may need medications for a short time, such as before or after surgery, while others may need medications for life.

This section provides information about the more common drugs used for CHDs, how they work, and the most common side effects. It also explains how to give drugs to babies and children safely, and provides tips for fitting drugs into your child's daily activities.

GIVING YOUR CHILD MEDICATIONS

Survival tips for giving drugs to babies and children

Keeping everyone informed

Tell the doctor, pharmacist or nurse if your child:

- has ever had an allergic reaction or bad side effect from any medicine,
- has any other diseases or conditions other than the one being treated,
- takes any other medicines or remedies, including non-prescription drugs, vitamins, and herbal remedies, because some may change the way your child's prescribed medicines work.

Know what medicines your child is on and keep an up-to-date list with you wherever you go. If any other caregiver (babysitters, teachers, and activity group leaders) will be giving your child medicine, make sure that the caregiver has this information and exact instructions on how to give it.

For more information about any medication, speak to your child's cardiologist, pharmacist or nurse.

Giving medications

- Give medicine exactly as prescribed, and for the length of time stated by the doctor. For non-prescription medicines, follow the instructions on the label unless told otherwise by your child's doctor, pharmacist, or nurse.
- Try to give the medicine to your child at the same time every day. To help you remember, choose times that are part of your child's daily routine.
- Refill prescriptions before your supply runs out, especially if you are going out of town or there is a public holiday when clinics and pharmacies may be closed.

Storage

- Keep medicines away from heat, sunlight, and moisture.
- Keep medicines in the fridge ONLY if told to do so.
- Check expiry dates, and discard expired medicine or medicine that is no longer needed, by returning it to the pharmacy for proper disposal.

CONSULT YOUR PHARMACIST

Talk to your pharmacist before buying any over-the-counter medicines such as cough and cold remedies for your child.

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TIME SAVING TIP

If your doctor has prescribed a refill, you can call your pharmacy ahead of time to reorder. Your pharmacist can then have the prescription ready for pick-up when you need it.

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Safety

- **Keep all medicines out of the reach of children.**
- Keep all medicines tightly capped in their original containers with childproof lids.
- Do not mix different medicines in one container.
- Do not use your child's medicines for any other family member. They must be seen and treated properly by a doctor.
- Keep the phone number of the poison control centre by the telephone in case of an accidental overdose.

Where do we get medicine for our child?

Most local pharmacies carry the more common drugs your child may need. Some specialized medicines may only be available at hospital pharmacies. Call ahead before going to your pharmacy to ask if they have the medicine prescribed for your child. It is a good idea to use the same pharmacy for all of your medication needs. This helps your pharmacist get to know your child's needs and ensures that all your child's medications can be safely used together.

How do we get our child to take the medicine?

Act as if medicine is part of the normal daily routine. Be positive, firm, and consistent with your child when giving medicine—this will help your child understand its importance.

You will have more success if your child is willing to take the medication. It can be helpful to give your child a choice such as what kind of juice to have afterwards. For young children, you may need to have a firm approach, and hold a toddler in your arms while you give the medicine.

Some tablets can be crushed or cut in half to make them easier to swallow. Check with your pharmacist to see if this is okay for each specific medicine. Tablets (whole, cut, or crushed) can also be hidden in ice cream or jam. Use a small amount of food to make sure your child gets all of the medicine.

For unpleasant-tasting medicines, have your child suck on ice cubes or a Popsicle™ just before taking the medicine. This helps to numb the mouth and taste buds and helps hide the flavour.

Liquid medicines can be given in a spoon or syringe. Some children will automatically place the tip of an oral syringe into their mouth. Gently depress the plunger a little at a time to allow your child to swallow.

Some children prefer to take medicine from a spoon. If so, measure it with the syringe and then empty the liquid onto a spoon before giving it.

Small rewards can be helpful in encouraging children to take medicines, particularly when it is a new medicine.

What should we do if our child vomits?

Repeat the dose only if your child vomits immediately after the medicine is given. Wait ten minutes before repeating the dose to allow your child's stomach to settle.

If your child vomits more than 60 minutes after the dose has been given, do not repeat it. Continue with your usual schedule. If you are unsure what to do, call your clinic nurse for instructions.

Call your doctor or clinic nurse if your child vomits with successive doses or for a few days in a row.

What should we do if we miss a dose?

Give the forgotten dose as soon as you remember. If it is more than half way to the next dose before you remember, skip the missed dose and carry on as usual afterwards. Never give a double dose.

How can we remember everything?

It can be helpful to have a calendar to remind you when the medicines are due, and when they are given (see *Medication List*, page 9-5).

Other ways of remembering are to use 'weekly pill boxes', or to pre-set alarm watches to remind you when medicines should be taken. These are also useful for older children who are learning to be responsible for their own pills.

Giving medicine with an oral syringe

Medicines are often given in liquid form because babies and children can swallow liquids more easily. Children's doses are so small that they cannot fit into tablets or capsules.

To make sure that your child gets the right dose, it is important to measure your child's medicine accurately. The nurse or pharmacist can show you exactly how much medicine to give your child.

There are several tools to help you do this:

- oral syringes,
- measuring spoons (available at the pharmacy), don't use your kitchen spoons,
- measuring cups (available at the pharmacy),
- graduated stoppers.

How to use an oral syringe

1. Pour a small amount of liquid medicine into a small clean cup.
2. Completely press down the plunger on the syringe.
3. Place the tip of the syringe into the liquid.
4. Holding the syringe firmly in one hand, use the other hand to pull the syringe plunger upwards.
5. Overfill the syringe by a small amount above the amount prescribed.
6. Press down on the plunger until it is at the marking on the barrel for the amount prescribed.
7. Remove the syringe from the liquid.
8. Make sure your child is sitting upright, and place the syringe between the cheek and gum.
9. Press down slowly on the plunger. Give small amounts so that your child has time to swallow.
10. When all the medicine has been given, rinse both parts of the syringe, and dry them with a clean towel.
11. You may give your child a small drink of water or juice afterwards to rinse the mouth and wash the medicine down.

CAUTION!

KITCHEN TEASPOONS AND TABLESPOONS VARY GREATLY IN THE AMOUNT THEY MEASURE

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DO NOT USE THEM TO MEASURE MEDICINES

MEDICATION LIST

Name: **Telephone Number:**

Address:

In case of emergency, contact:

Drug	Purpose	Dosage (note mgs and mls)	When to take	Special Instructions	Side Effects	Other

* Source: *Recovery Road*, Heart and Stroke Foundation.

Tips for travelling

For any trip:

- make sure you take enough medicine to last the whole time you will be away from home (not all pharmacies can make exactly the same medicine your child takes),
- if you are just going out for a day trip, prepare liquid medicine by drawing it up in a syringe and sealing the end with a stopper,
- remember to keep the medicine away from children (diaper bags can be interesting for toddlers to explore, so they are not the best place for medicines),
- ask your pharmacy for larger childproof containers for bottles and syringes.

For longer trips:

- take along the name and phone number of the doctor's office for re-ordering,
- take a list of all medicines,
- if you will be crossing several time zones, stagger the doses. For example, if a medicine is given every 12 hours, change doses by an hour or two each dose to get to the usual times in the new time zone.

MEDICATIONS COMMONLY GIVEN TO CHILDREN WITH A CHD

Many heart defects can be helped by medications. This section describes the medications commonly used for children with CHDs. You need to know why your child is on a particular medication so that you can understand the importance of taking the medications according to the doctor's instructions.

Most medications have both beneficial and unwanted side effects. Some side effects are simply bothersome, while others may concern you. You should know what to watch for with each medication so that you can notify the doctor if a problem comes up.

Please note that all of the possible uses, actions, cautions, side effects or interactions of this medication are not covered in this section. If you want more information about any medications, ask your child's doctor, pharmacist, or nurse.

Why are there different names for most drugs?

You may notice that many drugs have two (or more) different names—the chemical or generic name and the brand name (what a company calls the drug).

Each drug has only one generic name but may have several brand names. For example, propranolol, a generic name, is also called Inderal® by one drug company and Apo-Propranolol® by another.

For each drug listed in this section, the generic name is used first and at least one of the brand names is listed beside it. It is sometimes helpful to know both names, but be certain that both names refer to the same drug.

TRAVEL TIPS

MAKE SURE TO TAKE ENOUGH MEDICINE TO LAST THE WHOLE TIME YOU ARE AWAY

FOR A DAY TRIP - PREPARE LIQUID MEDICINE BY DRAWING IT UP IN A SYRINGE AND SEALING THE END

KEEP MEDICINE AWAY FROM CHILDREN

TAKE THE NAME AND PHONE NUMBER OF THE DOCTOR'S OFFICE

TAKE A LIST OF ALL MEDICINES

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REMEMBER

GIVE MEDICINE EXACTLY AS PRESCRIBED

GIVE THE MEDICINE AT THE SAME TIME EVERY DAY

REFILL PRESCRIPTIONS BEFORE YOUR SUPPLY RUNS OUT

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The drugs listed on the following pages include:

- Digoxin
- Diuretics
- Anticoagulants
- Antiarrhythmics
- Beta blockers
- Calcium channel blockers
- Angiotensin converting enzyme inhibitors (ACE) inhibitors
- Antibiotics
- Iron supplements
- Support drugs

Digoxin (Lanoxin®)

What does digoxin do? Digoxin (digitalis) is a medication that is used to strengthen the heartbeat. It also works to make sure the heart beats in a regular rate or rhythm.

What should we watch for if our child is on digoxin? There is only a small difference between the therapeutic (helpful) and toxic (harmful) blood levels of digoxin. Therefore, if your child loses appetite, is nauseated, or has diarrhea, call your doctor. Other symptoms that you should report to the doctor include slow heart rate, dizziness or fainting, and double vision or blurred vision.

How should our child take digoxin? Most times, digoxin is taken in a liquid or pill form, which is available in most pharmacies. Children that start digoxin in the hospital are sometimes given it intravenously (through veins).

Diuretics (water pills)

What do diuretics do? A diuretic, or water pill, helps your child's body get rid of any extra fluid as well as any minerals and salts (electrolytes) that retain water. This prevents fluid from building up in the body and decreases blood pressure.

When should our child take the water pills? Because water pills increase the amount of urine the body produces, it is best to avoid giving your child a water pill around naptime or bedtime. If the water pill is once a day, it should be taken in the morning after breakfast. For young children, if it is more than once a day, the last dose should be given in the early evening to avoid bedwetting.

Furosemide (Lasix®)

- **What should we watch for if our child is on furosemide?** You will notice that furosemide makes your child urinate more often. This is normal. If you notice the amount of urine is decreased, or your child's skin or mouth is dry, check with your doctor. These are signs that your child's body may have got rid of too much water.
- **To avoid dehydration**, children who are taking diuretics must be watched very carefully if they develop fever, have diarrhea, or are vomiting. Check with the doctor if your child has a dry mouth or is urinating less.

Other diuretics

- **Hydrochlorothiazide** (Hydrodiuril®)
- **Spironolactone** (Aldactone®)

Note: Furosemide liquid is available from most pharmacies but hydrochlorothiazide and spironolactone liquids are only made by certain pharmacies.

Anticoagulants

What do anticoagulants do?
Anticoagulants, often called "blood thinners", prevent the blood cells from sticking together and forming dangerous clots.

ASA, acetylsalicylic acid (Aspirin®)

- **Why does our child have to take ASA?** ASA is often used to relieve pain and reduce fever and swelling. In children with heart conditions, it is often used in small doses as a blood thinner.
- **What should we watch for if our child is on ASA?** ASA can irritate the lining of the stomach. If you notice red, pink, or black in your child's urine or stool, call the doctor.
- There is no evidence to show Reye's Syndrome is linked to the low-dose Aspirin® used to discourage clotting. If you have concerns about this, please speak to your child's cardiologist.

Warfarin (Coumadin®)

- **Why does our child have to take warfarin?** Warfarin is called a "blood thinner" because it increases the time it takes for the blood to clot. It works in a different way than Aspirin® or heparin (see Heparin, below). It is often used after surgery to prevent the formation of blood clots in artificial heart valves and blood vessels.
- **What should we watch for if our child is on warfarin?** Warfarin is a safe medication if it is taken according to instructions and monitored correctly. You should let your doctor know if you see any of the following signs: large bruises, cuts that don't stop bleeding, red or dark-brown urine, red or black stools, frequent or prolonged nose bleeds, coughing up blood, or unexplained, severe, or prolonged stomach pains.

Your health care team will usually spend time with you explaining some of the important things you need to know when your child is taking warfarin. Your child will need blood tests called "INRs" on a regular basis. You will also need to be aware of important interactions between warfarin and foods and drugs.

Heparin

- **When is heparin given?** Heparin is often the first anticoagulant that is used. It is commonly used for several days when a child first starts taking warfarin. This is to prevent clotting during the time when warfarin may not be at a high enough level in the blood to prevent clotting. This level is called the "therapeutic level".

Heparin is also used around the time of surgery instead of warfarin because its blood-thinning action can be reversed in less time. This allows a child to receive blood thinners almost up to the time of surgery and start them again right afterwards.

- **Why can't people go home on heparin?** Heparin can only be given intravenously (through the vein) or by a subcutaneous (under the skin) injection. This means that a health care worker must give the medication—either at the hospital, or at home if there is a family member qualified to give the medication. Regular blood tests are also needed when a child is on heparin. So travelling back and forth to the hospital for medications and blood tests is usually too inconvenient for families.

STORAGE

KEEP MEDICINES AWAY FROM HEAT, SUNLIGHT, AND MOISTURE

KEEP MEDICINES IN THE FRIDGE ONLY IF TOLD TO DO SO

DISCARD EXPIRED MEDICINE BY RETURNING IT TO THE PHARMACY

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CAUTION!

ASK YOUR HEALTH CARE PROFESSIONAL WHAT YOU SHOULD DO IF YOUR CHILD:

VOMITS OR

■

MISSES A DOSE OF AMIODARONE OR PROPRANOLOL

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- **What should we watch for if our child is on heparin?** If you notice red, pink or black in your child's urine or stool call your doctor.
- **Is low molecular weight heparin (LMWH) the same as heparin?** LMWH is similar to heparin, but it is like giving a small part of the heparin. It has similar effects and is used in children for similar reasons. Sometimes it is used because it needs fewer blood tests than heparin to see how it is working. It is more convenient than heparin, so some patients use once or twice daily injections at home. The LMWH most commonly used with children is enoxaparin (Lovenox®).

Antiarrhythmics

What do antiarrhythmics do? Antiarrhythmics (pronounced an-tee-ay-RITH-micks) are drugs used to help the heart beat more regularly. For example, if the heart is beating too fast, an antiarrhythmic slows the heart.

Antiarrhythmic drugs all work in different ways. If one doesn't work, try another one to find the drug that works the best for your child's heart.

Sotalol (Sotacor®)

What should we watch for if our child is on Sotalol? Call the doctor if you notice an unusual or slow heartbeat, swelling of the lower legs or feet, or cold hands or feet. If your child starts having nightmares, or has difficulty breathing, you should also call your doctor.

Amiodarone (Cordarone®)

What should we watch for if our child is an Amiodarone? Call the doctor if you notice unusual heartbeats, shortness of breath, tingling in fingers, toes, or significant changes in behaviour.

Protect your child from the sun with clothing, a hat, and sunscreen (SPF 30 or more) as your child is more likely to be sensitive to the sun and may burn more easily.

Ask your doctor or pharmacist before giving your child other medications, because some drugs interact with amiodarone.

If your child has to take amiodarone for a long time, his or her skin may become bluish-gray. It usually fades if treatment is discontinued.

Other antiarrhythmics

- **Digoxin** - see Digoxin, page 9-6.
- **Propranolol** - see Beta Blockers, page 9-8.
- **Flecainide** (Tambocor®).
- **Propafenone** (Rhythmol®).

Beta Blockers

What do beta blockers do? Beta blockers are useful for treating hypertension (high blood pressure), some types of arrhythmias (irregular and rapid heart beat), and for some kinds of congestive heart failure.

Which beta blockers are most commonly prescribed for children?

- **Propranolol** (Inderal®)
- **Atenolol** (Tenormin®)
- **Carvedilol** (Coreg®)
- **Metoprolol** (Betaloc®)

How do beta blockers work? Beta blockers work by blocking some of the effects of adrenaline and other related substances in the body. This reduces the amount of stress put on the heart.

Will our child feel any different on this medication? You may notice that your child's blood pressure is lowered, the pulse rate may fall and become more regular, or the pumping action of the heart may become stronger, improving circulation.

What should we watch for if our child is on a beta blocker?
Check with your doctor if your child has any of the following problems:

- breathing difficulty or wheezing,
- bluish-coloured fingernails or palms of hands,
- irregular or unusually slow heartbeat,
- severe dizziness or fainting,
- skin rash.

Calcium Channel Blockers

What do calcium channel blockers do? Calcium channel blockers are often used to treat high blood pressure. They relax the blood vessels. Verapamil is sometimes used to help control the rate of the heart.

Which calcium channel blockers are most commonly prescribed for children?

- **Nifedipine** (Adalat®)
- **Amlodipine** (Norvasc®)
- **Verapamil** (Isoptin®)

What should we watch for if our child is on a calcium channel blocker? In general, calcium channel blockers are well tolerated. Adverse effects, including flushing and headache, are more common in products that release quickly, like some forms of nifedipine.

You should help your child develop good teeth brushing habits to prevent gums from overgrowing.

Because some children become constipated while taking verapamil, make sure your child is drinking enough fluids.

Why are nifedipine and amlodipine used together? Nifedipine is a fast acting drug and amlodipine takes a lot longer. This means that a child is often started on nifedipine to figure out how much medication is needed. As the child's blood pressure becomes more stable, the short acting nifedipine is often replaced by amlodipine, which means you only have to give one dose once or twice a day.

Angiotensin Converting Enzyme Inhibitors (ACE inhibitors)

What do ACE inhibitors do? ACE inhibitors are used to treat high blood pressure and to keep the heart working properly in people with congestive heart failure.

Which ACE inhibitors are most commonly prescribed for children?

- **Captopril** (Capoten®)
- **Enalapril** (Vasotec®)
- **Ramipril** (Altace®)
- **Fosinopril** (Monopril®)
- **Lisinopril** (Zestril®)

Why was our child given captopril in the hospital and then sent home on enalapril? Of all of the ACE inhibitors, captopril and enalapril have been used the most for children. Captopril is often used first in order to assess how your child will respond to an ACE inhibitor. Because it works quickly, if blood pressure drops too low, it won't stay low for too long because the body gets rid of the drug quickly. Drugs like enalapril and ramipril are better for long term therapy because your child only has to take them once or twice a day.

Will our child feel any different on the medication? If your child feels dizzy, develops a rash, or has a continual cough you may wish to speak to your doctor.

CAUTION!

IF YOUR CHILD HAS BEEN ON A BETA BLOCKER FOR A WHILE AND STOPS TAKING THE DRUG SUDDENLY, IT MAY CAUSE: UNPLEASANT OR HARMFUL EFFECTS OR

- WORSEN YOUR CHILD'S CONDITION

CAUTION!

IF YOUR CHILD IS PRESCRIBED ANTIBIOTICS, IT IS IMPORTANT TO GIVE THE DRUG UNTIL THE ENTIRE PRESCRIPTION IS GONE SO THAT:

THE BACTERIA IS COMPLETELY KILLED

■

YOU PREVENT BACTERIA (THAT CAN'T BE DESTROYED BY ANTIBIOTICS) FROM GROWING.

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Antibiotics

What do antibiotics do? Antibiotics are drugs used to treat bacterial infections anywhere in the body. They are not used to treat infections caused by viruses. For children with a CHD, antibiotics are most commonly used to prevent bacterial endocarditis (see *Infection Called Bacterial Endocarditis*, page 2-14).

What should we watch for? The most common side effects of antibiotics are diarrhea, nausea, vomiting, and rash.

Antibiotics can sometimes cause an allergic reaction. Call your doctor if your child experiences a rash or hives, swelling of the face, lips, or difficulty breathing.

Acetaminophen (Tylenol®, Atasol®, Panadol®, Tempra®)

What does acetaminophen do? Acetaminophen relieves pain and reduces fever.

Will our child feel different on this medication? Side effects are rare when taken as directed.

Iron supplements - ferrous gluconate or ferrous sulphate

What do iron supplements do? Iron supplements are given to children who:

- need more iron than is in their normal diet,
- have a problem absorbing iron,
- lose too much iron because of bleeding.

How should we give this medication? To ensure your child gets the most benefit from the supplement, give it with water or orange juice on an empty stomach—at least 20 minutes before or 2 hours after meals.

For liquid medicines, measure with a spoon, syringe, or the dropper provided.

To avoid tooth staining, mix the dose in water or juice and have your child drink it with a straw.

If using a dropper:

- place the medicine well back on the child's tongue and follow it with a small drink,
- if tooth stains occur, they can be removed by brushing with baking soda or hydrogen peroxide 3%.

For iron to be absorbed, there must be acid in the stomach. The following drugs decrease the amount of acid in the stomach, and should not be given at the same time as iron supplements:

- **Cimetidine** (Tagamet®)
- **Ranitidine** (Zantac®)
- **Famotidine** (Pepsid®)
- **Omeprazole** (Losec®)
- Over-the-counter **antacids** or **calcium supplements**

If your child is on any of these medications, give them at least 30 minutes after the iron.

Avoid giving these foods for 1 hour before or 2 hours after iron supplements because they decrease the amount of iron absorbed:

- eggs and cheese,
- tea and coffee,
- whole grain breads and cereals.

What should we watch for? Iron supplements can cause stomach upsets. To prevent stomach upsets, give the medicine with a small snack.

Some children have one or more of the following side effects:

- nausea or vomiting,
- constipation or diarrhea,
- heartburn.

These side effects should go away as your child's body gets used to the drug. Discuss the side effects with the doctor if they continue.

Call the doctor right away if your child has one or more of the following:

- stomach pain or cramping that lasts more than a few hours,
- chest or throat pain with swallowing,
- blood in the stools, which can appear black or red,
- any other symptoms of concern to you.

Note: Stools normally turn black when iron is taken. Contact the doctor if they are jet black, shiny or tar-like in appearance, particularly if your child is feeling sweaty or faint.

Support drugs

A variety of medications can be used after surgery to help support the heart muscle. They are given at a controlled rate by intravenous (IV) pump, and are decreased (weaned) slowly as the heart gets stronger.

Epinephrine/Adrenalin - speeds up the heart rate and makes the heart muscle contract harder.

Dopamine/Intropin®/Dobutamine/ Dobutrex® - helps raise blood pressure by narrowing the blood vessels in the arms and legs.

Isoproterenol/Isuprel® - increases how much blood the heart is able to pump (cardiac output) and makes the heart work harder.

Milrinone/Primacor® - increases how much blood the heart is able to pump without making it work too hard.

Nitric oxide/Inomax® - a short acting, inhaled medication that lowers the blood pressure in the lungs. Often used to treat **pulmonary hypertension** (high blood pressure in the lungs).

Prostaglandin/ProstinVR® - an intravenous drug given to babies to keep the ductus arteriosus open until a hole can be created between the two upper chambers of the heart.

CAUTION!

ACETAMINOPHEN CAN BE VERY HARMFUL IF TOO MUCH IS TAKEN. WHILE ON THIS MEDICINE, DO NOT GIVE YOUR CHILD ANY OTHER PRODUCTS CONTAINING ACETAMINOPHEN. READ LABELS CAREFULLY.

MEASURE WITH SPECIALLY MARKED SPOON, CUP, ORAL SYRINGE, OR DROPPER PROVIDED.

REFERENCES FOR MEDICATIONS

- If you would like more information about the medications that your child is taking, contact your pharmacist or refer to one of the many excellent reference books for parents, including:

Advice for the patient, drug information in lay language. 21st Ed. USP DI 2001.

www.nlm.nih.gov/medlineplus

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Immunizations

IMMUNIZATION SCHEDULE

ASK YOUR DOCTOR ABOUT MODIFYING YOUR CHILD'S IMMUNIZATION SCHEDULE: BEFORE AND AFTER SURGERY OR ANY MAJOR PROCEDURES

■

IF YOUR CHILD HAS RECEIVED BLOOD PRODUCTS

Immunizations are an important part of caring for your child and maintaining optimum health.

For regular immunizations, and if your child has a spleen that is not working properly, ask your health care professional if the following vaccines are okay:

- Chicken pox vaccine,
- Annual flu vaccine,
- Hepatitis B vaccine,
- RSV vaccine,
- Meningococcal vaccine,
- Prevnar (pneumococcus vaccine).

(See *Immunization Record*, page 13-3)

Nutrition and feeding

""We had to weigh him before he ate and after and try to estimate how much he had eaten. and then he would throw it up, and we had to decide how much nutrition he was getting. It was awful."

PARENT

Children with a CHD may have problems getting the nutrients they need to grow and develop properly. This depends on the type of heart condition. Your child may need a special diet or a different way of feeding or eating, called "feeding strategies".

A meal should be a pleasant and positive time for the whole family. It is a chance for you and your child to spend time together, and for your attachment to each other to grow. It is also a chance for your child to practise new skills and learn healthy eating habits. When a CHD interferes with eating, it can upset your child and disrupt your whole family. Therefore, it is important to spot nutrition and feeding problems early and find solutions quickly.

What are the common types of nutrition and feeding concerns?

Four common nutrition and feeding problems are described on the following pages.

Difficulty getting enough nutrients

If children cannot get enough nutrients, they will grow slowly. Most healthy babies double their birth weight by the time they are four or five months of age. Babies with a CHD often grow more slowly. This slow growth can continue throughout childhood. Children with CHF often grow normally in height, but may gain weight more slowly than healthy children.

There are many causes of slow growth, including:

- difficulty getting enough calories and nutrients by breastfeeding, drinking, or eating,
- not enough energy to feed or eat properly because too much energy is used to keep the heart pumping and the lungs working.

Try shorter and more frequent feedings or meals to help babies and children gain weight and save energy. A diet or formula high in

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calories and nutrients can be helpful. Special products can be added to breast milk to increase calories.

Difficulty eating safely

Some children have difficulty coordinating the movement of the tongue, jaw, and lips. This makes it hard for them to suck, chew, or swallow (sometimes called "oral motor skills"). Children with a CHD, congestive heart failure, chronic illness, or long-term tube feeding sometimes have this problem. Such children need help and encouragement to learn how to suck, swallow, and chew on their own.

Sucking and swallowing problems can cause aspiration (breathing fluids or food into the lungs). If your child is having trouble feeding safely, the doctor may request a feeding assessment and special tests to see how your child swallows. You may need to change what your child eats and how it is eaten.

Doesn't want to eat

Children with heart defects may not want to eat because it tires them out. They may also be afraid of choking. Children who are often sick may connect eating with vomiting. Some children are fearful of foods of different colours, textures, or flavours. Other children don't like special diets and pressure to gain weight. Team members can give you ideas to encourage your child to eat.

Difficulty with breastfeeding

Some babies have trouble with breastfeeding, even if they don't have a CHD. They may be sleepy, or may have trouble latching onto the nipple. A "lactation consultant" can help with these problems.

How are nutrition and feeding problems identified?

As a parent, you may be the first to notice that your child has a nutrition or feeding problem.

You may notice that your child:

- is having trouble sucking, chewing, or swallowing,
- is often too tired to feed or eat,
- does not appear to be gaining enough weight.

The health care team will be checking your child at the clinic or in the hospital. If you are concerned that your child cannot swallow safely (for example, he or she coughs or chokes during feeds), the team may ask for a special X-ray feeding study. Even if there is no obvious problem, the doctor may order a nutritional assessment.

The nutrition and feeding team members include the dietitian, occupational therapist, and lactation consultant.

- The **dietitian** checks to see whether your child is eating well and growing fast enough. The dietitian may recommend a different diet. The dietitian also provides nutritional counselling and education.
- The **occupational therapist** (OT) may do a feeding assessment for a baby or child who is having trouble sucking, chewing, or swallowing. If necessary, the OT will help your child develop better feeding or eating skills. The OT may also suggest different feeding strategies.
- The **lactation consultant** provides lactation support and counselling for mothers who are breastfeeding their babies or expressing breast milk. Your nurse and lactation consultant will help you with breastfeeding problems.

"The dietitian was so instrumental in sorting out Zoe's complex feeding situation last spring. She started at square one and slowly upped Zoe's feeds so that we went home at a comfortable level and never really looked back.

PARENT

BREASTFEEDING

Human milk is recommended for almost all babies because:

IT CONTAINS THE BEST NUTRIENTS FOR THE BABY

■

IT IS EASIER FOR THE BABY TO SUCK, SWALLOW AND BREATHE

■

THE BABY GETS MORE OXYGEN

■

IT CAN PROVIDE COMFORT TO YOUR BABY DURING OR AFTER A PAINFUL PROCEDURE

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How are common nutrition and feeding problems managed?

The table (*Tips for managing common nutrition and feeding problems*) on page 9-15 contains general information to help you manage common feeding problems. The cardiology team members will also give you instructions. If you have concerns regarding your baby's or child's nutrition or feeding, contact your dietitian, occupational therapist, or lactation consultant.

Breastfeeding

Human milk is recommended for almost all babies because it contains the best nutrients for the baby. It is easier for the baby to suck, swallow, and breathe during breastfeeding and the baby gets more oxygen. Breastfeeding can also provide comfort to your baby during or after a painful procedure, surgery, or separation.

Breastfeeding is usually possible. If your baby is not well enough to breastfeed, you can "express" your breast milk until your baby is able to breastfeed again. If needed, special additives and pumping techniques can give your baby extra calories while you continue breastfeeding. Your child's nurse or lactation consultant will show you how to express your breast milk. Breast pumps are available for use in the hospital. Pumps may also be rented for use at home if needed.

Baby formula

Babies who are on standard baby formulas instead of breast milk may also need extra calories to gain weight. They may be placed on an increased calorie baby formula. The number of calories in baby formula is measured in kilocalories (kcal) per ounce (oz) or kilocalories per 100 millilitres (mL). Standard baby formula is 20 kcal/oz (67 kcal/100mL), and increased formulas may have more. For example, 24 kcal/oz (80 kcal/100mL) or 27 kcal/oz (90 kcal/100mL). You may not be able to buy these higher calorie formulas, but you can make them from powder or liquid concentrate. The dietitian will give you a special recipe for high calorie formulas.

Normal feeding and solid foods

Babies, children, and teens should eat a normal, healthy diet for their age. The dietitian can tell you what is right for your child at different ages.

Start giving babies solid foods when they are between four and six months old. The transition from baby food to adult food should be the same as for healthy children.

Some babies may take more time to learn new feeding skills because of their CHD or because they are always ill. In this case, continue to offer foods that your baby can manage based on their developmental and physical readiness. Delaying the introduction of solid foods may lead to poor acceptance of foods later on.

TIPS FOR MANAGING COMMON NUTRITION AND FEEDING PROBLEMS

Problem	Options
Difficulty getting enough nutrients	■ Provide a diet or formula high in calories and nutrients. ■ Add special products to breast milk, formula, or foods. ■ Provide nutritional drinks. ■ Consider supplemental tube feeding if your child is unable to meet their nutritional needs by drinking or eating. ■ Provide higher fat content breast milk (hindmilk). ■ Provide small, frequent feeds. ■ Provide a diet/formula high in calories if the child cannot drink or eat normal quantities. ■ Limit the length of feedings/meals so the child does not become too tired.
Difficulty with eating safely	■ Position the baby/child carefully when breastfeeding, bottle feeding, or feeding solids. ■ Use techniques such as pacing your baby during breastfeeding or bottle feeding. ■ Try different food textures (for example, thicker liquids) and different methods of feeding. ■ Try different feeding equipment such as bottles, nipples, and cups.
Doesn't want to eat	■ Provide limits and guidelines that encourage good eating habits and positive feeding behaviours. ■ Try changing where your child eats and who is in the room during feeds. ■ Learn your child's feeding cues and signals (how your child is feeling about eating and about specific foods). ■ Become aware of how you interact with your child during feeds. ■ Cuddle your baby at the breast, skin to skin, even when you do not want him or her to feed.
Difficulty with breastfeeding	■ Help your baby latch onto the nipple. ■ Try different breastfeeding positions. ■ Ask for an assessment of breastfeeding and milk supply.

TUBE FEEDINGS

There are two types of common feeding tubes:

NASOGASTRIC (NG) WHICH IS PLACED IN THE STOMACH THROUGH THE NOSE

■

GASTROSTOMY TUBE (G-TUBE) WHICH A SURGEON PLACES INTO THE STOMACH THROUGH THE SKIN

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Special diets or dietary modifications

Cutting back on some things, such as fluids and salt, can help in managing some heart conditions. The dietitian will help with this.

Some children need less fluid to manage their medical condition. This is called fluid restriction. Fluid restrictions can make it hard for your child to get enough calories and nutrients to grow and develop properly. If so, you may need to change your child's diet or provide a special diet. Your child may also need to avoid salty foods and limit how much salt is added to the food.

A low fat diet is usually not recommended for babies and children. A few children have conditions such as **chylothorax** that require a diet low in a certain type of fat. Fat additives and high fat foods are often included in high calorie diets because they are high in calories.

Vitamin and mineral supplementation

Most babies who are breastfed do not need routine vitamin supplements; but Vitamin D supplements are recommended. Formula-fed babies who are gaining weight well do not need supplements. Babies who often have trouble drinking enough formula many need a supplement.

Babies who do not have enough iron in their blood need an iron supplement. Ask your doctor whether your baby or child needs an iron supplement.

Children and teens who follow *Canada's Food Guide to Healthy Eating* do not need supplements. You can get a copy of the guide from your dietitian or public health nurse.

Financial support for special formulas and products

Special formulas and food products can be very expensive. Sometimes you can get financial help for buying these products. The social worker or clinic nurse can find out if you are eligible for financial help.

Maintaining cultural beliefs and practices

If your family has cultural beliefs that involve food, these practices can be considered in planning what and how your child eats. The dietitian, lactation consultant, or clinic nurse can help you. If your child is in hospital, you may be allowed to bring in food from home. Check whether you can bring favorite foods that are not on the hospital menu. If your child is on a special diet, check with the dietitian to be sure that the food is okay.

Tube feedings

Some children who have trouble getting enough calories or nutrients by eating or drinking, may need a feeding tube.

There are two common types of feeding tubes:

- **nasogastric** (NG) **tube**, which is placed into the stomach through the nose,
- **gastrostomy tube** (G-tube), which a surgeon places into the stomach through the skin. G-tubes are used for long term feeding problems.

The type of tube depends on your child's age and nutritional needs and how much your child is able to eat and drink. The cardiology team will train you and give you guidelines.

Dental care

Why is dental care so important?

Children with a CHD need special attention to their teeth for several reasons:

- They have poorer oral health than other children, leading to more cavities, gum disease, and chances for infection such as bacterial endocarditis (see "*Infection called bacterial endocarditis*", page 2-14).
- Unusual conditions such as enamel hypoplasia (the hard coating on the teeth doesn't form properly) in the baby teeth are twice as common in children with CHD as in other children. Although the permanent (adult) teeth are usually not affected by these problems, it is important that baby teeth form properly because they guide the permanent teeth into the right position.
- Medications such as Digoxin, Lasix®, Tylenol® and others are usually sweetened with sugar. Children with CHDs often have to take these medications on a regular basis for a long time. The sugars collect on the teeth and add to tooth decay.
- Some cardiac medicines such as Lasix® can decrease the saliva, leading to a build-up of plaque on the child's teeth. Plaque build-up is one of the main causes of tooth decay.
- Dental care often seems less important than other problems for children with more serious or complex CHDs.

How can I help my child's teeth develop normally?

- Start early. Don't settle your baby to sleep with a bottle of milk or juice in his or her mouth. Milk, juice, and formula all contain sugar, which can cause tooth decay when allowed to pool in the mouth.
- Begin cleaning your baby's teeth twice a day as soon as they appear. Use a soft baby toothbrush or small piece of terry cloth.
- Have your child's teeth checked at one year old, and begin regular check-ups twice a year at ages 2-3. Ask for tips on brushing, flossing, fluoride, and preventing tooth injuries.
- Young children require assistance with tooth brushing to ensure that they have cleaned all tooth surfaces adequately.
- Use a tiny amount of toothpaste containing fluoride to brush your child's teeth. Fluoride helps teeth develop. Don't let your child eat the toothpaste, since too much fluoride can be harmful.
- Don't let your child snack more than 3-4 times a day. Frequent eating and drinking keeps the teeth covered with acid, and there is not enough saliva to remove the acid. This adds to tooth decay.
- Give medicines **before** brushing your child's teeth.
- Like many children, your child may need braces to straighten his or her teeth. Most braces are now brackets bonded to the teeth, but some orthodontists choose to use metal bands. When these are first put on, there is some bleeding, so antibiotic protection will be needed. Antibiotics will not be needed for adjustments to the braces.
- Like most children, your child should wear a mouth guard for contact sports.

For more tips on caring for your child's teeth, talk to your dentist.

TEETH TIPS

DON'T SETTLE YOUR BABY TO SLEEP WITH A BOTTLE OF MILK OR JUICE IN HIS OR HER MOUTH

MILK, JUICE, AND FORMULA ALL CONTAIN SUGAR, WHICH CAN CAUSE TOOTH DECAY

CLEAN YOUR BABY'S TEETH TWICE A DAY

USE A SOFT TOOTHBRUSH OR SMALL PIECE OF TERRY CLOTH

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COMPLIMENTARY THERAPIES

Complimentary therapies are chosen for many reasons:

TO IMPROVE A CHILD'S GENERAL HEALTH

TO PROVIDE A CHILD WITH MORE HOLISTIC OR NATURAL FORMS OF THERAPY

TO FEEL THAT ALL POSSIBLE APPROACHES ARE BEING TRIED

TO MINIMIZE SIDE EFFECTS OF CONVENTIONAL THERAPIES

TO PROMOTE A SENSE OF WELL-BEING

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REFERENCES FOR DENTAL CARE

- Hallett, K.B., Radford, D. J. and Seow, W.K. Oral health of children with congenital cardiac diseases: A controlled study. *Pediatric Dentistry* 14(4) July/August, 1992.
- BC Children's Hospital, Department of Dentistry.
- Saunders, F. E., Roberts. G. J. Suwanprasit, A. Dental Disease, caries related microflora and salivary IgA of children with severe congenital cardiac disease: an epidemiological and oral microbial survey. *Pediatric Dentistry* 18(3) 1996.
- "Your Child's Dental Care", American Heart Association booklet, 2001.

Complimentary and alternative therapies

What are complimentary and alternative therapies?

Complimentary therapies (often called integrative therapies) and alternative therapies include many different types of treatments, such as acupuncture, herbal and vitamin therapy, therapeutic touch, homeopathic treatments, and mind-body therapies such as bio-feedback.

Alternative therapies are those which are used *instead* of conventional treatments. Complimentary therapies are those which can be provided *in addition* to the treatment prescribed by your medical doctor. These treatments are outside of conventional medicine - they are not taught in most medical schools in the western world, and are not practiced by most medical doctors.

Many of these therapies are "holistic therapies" - they focus on the whole person, including the mind, body and spirit, instead of the disease.

Over the past ten years the use of these therapies has almost doubled. Almost half of Canadians now use complimentary and alternative therapies to maintain their health or manage a medical condition. More and more families are asking questions about using complimentary therapies while in hospital. This section provides information about complimentary therapies so that you can make an informed choice about whether these therapies are right for your child.

What are the most common types of complimentary therapies?

There are many different types of complimentary therapies.

Here are a few examples:

bodywork
massage therapy, reflexology, and hydrotherapy

energy therapies
healing touch, therapeutic touch, reiki, acupuncture, acupressure, biokinesiology, chigong, sound therapy, aromatherapy, bach flower remedies, homeopathy, and magnetic therapy

dietary or metabolic therapies
nutritional supplements, herbal therapy, and chelation

psychological and behavioural therapies
imagery, visualization, psychotherapy, hypnosis, biofeedback, meditation, dance therapy, art therapy, music therapy, counselling, prayer, spiritual/religious and cultural rituals

Are these therapies available to our child in hospital?

Except for some of the psychological and behavioural therapies, most of the therapies previously listed are not formally available in hospital. Many behavioural therapies are practised by nurses, child life workers, hospital chaplains, psychologists, and First Nation's advocates. There is a small but growing use of therapeutic touch and art therapy provided by nurses and other health care professionals in some hospitals, and an art therapist may be available.

How do we learn more about complimentary therapies?

When considering the use of complimentary therapies in your child's care, it is helpful to know why you want the therapy. Ask yourselves whether you are looking for a cure, improved quality of life for your child (for example, comfort or reduction of side effects), more control of your child's health care, or something else. Different therapies are used for different reasons.

Once you know the purpose of the therapy, do some research. Because most healthcare professionals within the hospital are not experts in these therapies, you will need to do your own research.

Find out how the therapy works, what it involves, when it is best used, and how much it costs. Try to determine whether the therapy has been used on children with heart conditions, and find out if there is any research that explains the advantages and disadvantages. When choosing a therapist, find out about his or her level of training and experience.

When you have all of the information, weigh the benefits and risks (potential harm or side effects) of the therapy. This is an important step, and should be done when evaluating any kind of therapy. You may wish to talk to others in making your decision. Finally, keep in mind that you will be responsible for any choices you make. Tips and resources to start you on your search for information are included at the end of this section.

Do we need to tell anyone about our decision to use this therapy?

It is always wise to discuss all aspects of your child's health with the people involved in your child's medical care. Some therapies may interact with the conventional treatments your child is receiving. Some herbs affect certain drugs; for example, goldenseal may increase the coagulation effect of coumadin, changing how the blood clots.

You and the doctor can discuss the benefits and risks of all therapies on your child's health. The more you know about the specific therapy, the better. If you find that your choice of therapy is not supported by your health care provider, you may want to speak with another health care professional for a second opinion.

Tips and resources for choosing the therapy that is right for you

Learn all you can about the treatment:

- If you have Internet access, there is alot of information available, but be careful to choose sites that do not seem to be pushing one particular treatment. Keep in mind that the information may not be accurate because anyone can put information on the Internet.
- Visit the resource library in your hospital, your local community library, or special libraries such as those at a college or university. Look for books and journals on alternative and complementary medicine.
- Visit bookstores. There are many books on health, wellness and alternative therapies in popular and alternative bookstores.

TIPS AND RESOURCES

IF YOU HAVE INTERNET ACCESS, THERE IS ALOT OF INFORMATION AVAILABLE

VISIT THE RESOURCE LIBRARY IN YOUR HOSPITAL OR LIBRARY

VISIT BOOKSTORES

TALK TO YOUR HEALTH CARE PROFESSIONALS

TALK TO OTHER PARENTS WHO HAVE TRIED THE THERAPY

CONSIDER WHETHER COST OF TREATMENT IS JUSTIFIED

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GATHER AND COMPARE

Gather information from as many places as possible, and compare it all before making your decision. Remember that when you choose an alternative medicine, it is your responsibility to be well informed.

- Talk to your health care professionals (the staff nurse, clinical nurse specialist, outreach nurse, clinic nurse, child life specialist, cardiologist, surgeon, pharmacist, physiotherapist, pain nurse clinician, anaesthetist, social worker, chaplain and First Nations advocate) and find out what they know about the therapy you are considering. They may already know whether the therapy can safely be taken or used with the treatment your doctor has prescribed, or they may be willing to find out for you. They may also have information about whether the therapy is effective for your child's particular health condition.
- If possible, talk to other parents/people who have tried the therapy. Who recommended it to them? Did it work? Were there any side effects?
- Talk to the therapists and find out what experience and training they have in providing therapy for people with the same or similar conditions. Ask if you can speak with one or more of their clients.
- Visit health food stores. Most of them have pamphlets about the products they sell.
- Visit herbal therapy shops. The staff members are usually well informed on supplements and herbal therapies. Some have licensed herbal practitioners on site. Follow up with your own reading.
- Contact the Health Protection Branch of Health Canada for general information on control of alternative therapies.
- Contact the organizations that govern specific therapies, such as your provincial chiropractic association.
- Choose a qualified (certified) and experienced health care or alternative medicine practitioner to dispense the treatment. Some people who dispense these therapies have no special training to do so. For example, not everyone who works in a health food store has specialized training.
- Question any information given to you about the therapy. A therapy claiming to be "natural" may still be unsafe. Therapies that promise "miracle cures" should make you suspicious.
- Consider whether the cost of the treatment is justified. For example, some herb and vitamin supplements are very expensive and contain nothing more than vitamins and minerals that your child can get by eating a healthy diet.

Gather information from as many places as possible, and compare it all before making your decision. Remember that when you choose a complimentary therapy, it is your responsibility to be well informed.

REFERENCES FOR ALTERNATIVE THERAPIES

- Canadian Medical Association: A Patient's Guide to Choosing Unconventional Therapies, *Canadian Medical Association Journal,* 1998:158(9).
- Canadian Pediatric Society. Nutrition for Healthy Term Babies. Canadian *Journal of Dietetic Practice and Research*, 1998:59(2); 93-96.
- Dupont Pharmaceuticals: *Herbal Information Chart.*
- Greecher, C. P. Congenital Heart Disease. *Nutritional Care of High-Risk Newborns*. Edited by S. Groh-Wargo, M. Thompson, J. Cox. Precept Press Inc., Chicago 1994, p266-275.
- Marion, B. L, O'Brien, P. and LoRe, H. Oxygen Saturations During Breast and Bottle Feedings in Babies with Congenital Heart Disease. *Journal of Pediatric Nursing,* 10(6):1995; 360-364.
- Angus Reid Group, *Canadians and Alternative Medicines and Practices*, September/October, 1997.

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Cultural and spiritual beliefs

How can we integrate our cultural and spiritual beliefs into our child's care?

The health care team wants to support you and your spiritual and cultural beliefs while your child is in the hospital. Tell them what you need. Most hospitals also have a chaplain, social worker, or a First Nation's advocate available to help.

If you have spiritual beliefs about the use of blood products, please discuss your concerns with your health care team.

What help can the chaplain provide?

Whatever your beliefs may be, chaplains are often available to help you:

- explain your cultural and spiritual beliefs to the staff,
- find community resources to support your needs,
- support you in ethical dilemmas or decision making,
- explore your spirituality and spiritual resources.

See the *Directory*, page 13-4 to record a chaplain as a contact.

What help can the First Nation's Patient Advocate provide?

When looking at health and wellness, some First Nation's people examine their own emotional and spiritual well-being. The First Nation's Patient Advocate can connect patients and families with elders who help by doing talk therapy and energy work. The Advocate can also organize traditional ceremonies for patients and their families (of any heritage) to help ease some of the distress many have in hospital.

See the *Directory*, page 13-4 to record a First Nation's Advocate as a contact.

HELP IS CLOSE

The chaplain can help you:

EXPLAIN YOUR CULTURAL AND SPIRITUAL BELIEFS TO THE STAFF

■

FIND COMMUNITY RESOURCES TO SUPPORT YOUR NEEDS

■

SUPPORT YOU IN ETHICAL DILEMMAS

■

EXPLORE YOUR SPIRITUALITY

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