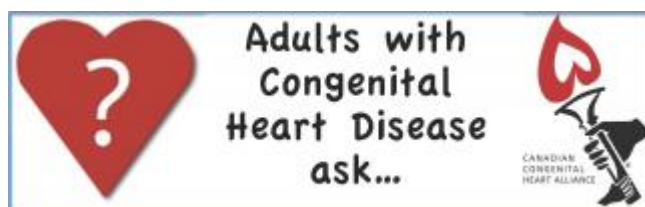




## CHD patients ask...



These are some of the questions we've collected from our CHD patient-nurse sessions at the CCHA Beat Retreat camp. We'll be adding to this section as time goes by so please check back.

A big thank you to several nurses at Alberta hospital congenital heart centres for taking the time to provide the answers.

### Questions:

1. [My pills make me feel worse when I take them. What can I do about it?](#)
2. [Does having scar tissue at the top of the ventricles and between the pulmonary artery and aorta cause fatigue?](#)
3. [Do beta-blockers cause depression?](#)
4. [Do antidepressants cause weight gain?](#)
5. [Do beta-blockers cause weight gain?](#)
6. [Can beta-blockers make you feel sluggish?](#)
7. [Can the pericardium get big?](#)
8. [Should I be concerned about occasional chest pain \(e.g. heavy feeling, racing heart, shortness of breath\)?](#)
9. [What is the life expectancy for someone with tricuspid atresia?](#)
10. [Can someone with a half heart \(single ventricle\) carry a baby to term?](#)
11. [What is the annual check-up process?](#)
12. [How should I take my medications properly, especially if I take them for multiple problems?](#)
13. [You hear about people dropping dead during exercise, even in healthy people. How do we know when it's too much?](#)
14. [Do traditional Chinese medicines fix some heart problems?](#)
15. [What kind of vitamins, supplements, and herbs should CHD patients avoid?](#)
16. [Can you explain the issues regarding a unicuspid valve.](#)
17. [Can you speak about issues concerning birth control and family planning when you have not had your valve replacement yet versus having it replaced before pregnancy.](#)
18. [Have you seen other cardiac patients complaining of migraines, headache and dizzy spells? Do you think that neurology issues could be related to my heart condition?](#)
19. [When I sleep I often put my arm above my head because my chest sometimes feels congested. Is this normal?](#)
20. [What is the difference between dynamic and static exercise?](#)
21. [In the case of swollen feet and ankles and one side is more than the other, is this a cardiac issue or a circulation issue?](#)
22. [What will medicine and medical care look like 20 years down the road?](#)
23. [If you black out or pass out, when should you go to the hospital or call your doctor?](#)

[24. Why and what causes clubbing? Does it develop/start in the womb or after birth?](#)

[25. What should happen at the outpatient appointment? What questions should be asked?](#)

[26. Is it safe to do push-ups if I have an implantable automatic cardioverter-defibrillator \(AICD\)?](#)

[27. After a recent ablation my resting heart rate went from 68 to an average of about 50. Would that explain my lack of energy?](#)

[28. My LV \(LV= left ventricle\) is enlarged and my LV function has been said to be Grade 2-3. What does that mean?](#)

[29. What is 22q microdeletion?](#)

[30. What age is the cut-off for receiving a heart transplant?](#)

[31. What is the potential life expectancy of a congenital heart patient?](#)

## **Answers**

1. If you can give your doctor specifics as to how you feel worse this can help determine if it is being caused by your medication. Write down exactly what you feel and how long after the medication this happens and if it happens every time. By working together with your doctor you may find that the dosage or timing can be adjusted or it may be that your symptoms are not related to the medications.

2. Scar tissue does not cause fatigue. It can however cause your heart to have some irregular heart rhythms that could cause fatigue. It can be difficult to discover the cause of your fatigue because fatigue can be caused by many things and it doesn't have to be related to your heart.

3. While it isn't a common side effects beta-blockers can cause depression in some people. If you have noticed changes in your mood since starting your beta-blocker you should discuss this with your family doctor.

4. Yes, some antidepressants can cause weight gain in some people. The weight gain isn't usually seen until you have been on the antidepressants for 3-6 months. For most people the weight gain is minimal. If you do notice a weight gain do not stop the medication. Discuss this with your family doctor and decide if changes need to be made.

5. Yes beta-blockers can cause weight gain. Doctors are not certain the exact reason why some beta-blockers can cause weight gain but it's usually not more than about 4 pounds. If you notice weight gain more than 4 pounds you should discuss this with your doctor.

6. Beta-blockers can cause fatigue in some people. Usually it settles down after the first couple of weeks. In a small percentage it can cause extreme fatigue. If the fatigue continues or is interfering with activities of daily living this should be discussed with your doctor. Sometimes changing the dose or changing the time the medication is taken is needed. It could also be that a change of medication is needed.

7. The pericardium is the lining or sac that surrounds the heart. It does not get larger. If the lining becomes inflamed it is called pericarditis. If some fluid collects between the heart and the lining it is called a pericardial effusion.

8. There are many non-heart related reasons for occasional chest pain, including musculoskeletal injury, costochondritis, asthma, bronchitis, gastroesophageal reflux, etc. Most times occasional chest pain that is brief in nature is probably not concerning. Pain that last for several hours, or the sensation of a racing heart that lasts longer than 15-20 minutes, should be assessed. Patients can discuss concerns with their family physician or can call their adult CHD clinic to consult with one of the nurses by phone.

9. Long-term quality of life following a Fontan operation is generally good. Complications in adulthood include heart rhythm problems, lung problems, or digestive problems. It is very important that patients with tricuspid atresia have lifelong follow-up in an adult CHD center where specialized care can be provided by expert clinicians.

10. Women born with a single ventricle may be able to safely and successfully carry a pregnancy to term. Patients with single ventricle may face impaired fertility. Women born with a single ventricle should discuss pregnancy with their adult CHD cardiologist to ensure they are good candidates.

11. The annual check up process generally includes a clinic visit and consultation with the adult CHD cardiologist and nurse. The visit also usually included an echocardiogram and may also include other testing such as holter monitoring, exercise stress test, or other diagnostic imaging such as CT or MRI.

12. Taking medications properly and safely is best accomplished by communicating with your pharmacist, primary care physician, and adult CHD specialists. Knowing all medications and supplements that a patient is taking will ensure that possible interactions or side effects are avoided.

13. Physical activity is a very important aspect of health and well-being. "Dropping dead" during exercise is extremely rare, but well publicized. The shock factor, and the rare times it occurs, is often why it makes the news. People in the general population who die during regular exercise often have an underlying issue that they were unaware of. There are many positive benefits, both for our physical and mental health, from regular exercise. Being as physically active as you can be would be encouraged. Regardless of the type of heart condition you have, everybody can walk. It is a safe (and free!) form of exercise. A majority of congenital heart disease patients have few or no activity restrictions; this even includes competitive sports. You should discuss physical activity and whether you have any restrictions to your activity level with your cardiologist regularly (for example at every clinic visit).

14. Congenital heart disease is not like acquired heart disease. To use an analogy, if you think of your heart as a house - congenital heart disease is a problem with the actual blueprint of how your heart was made. Traditional Chinese medicine cannot "fix" how the heart was made - once made, a heart cannot be made again. If you are considering using traditional medicines to treat some of the symptoms you have, it is very important to discuss what you would like to use with your congenital heart care team. Some may be safe to use, and other treatments may be too risky. Your cardiologist and congenital care team can best help you make a safe decision.

15. Generally speaking, the issue with taking vitamins, supplements, and herbs is the risk of interfering with some medication that you may be taking to help your heart. Before taking any new medication (whether an over-the-counter vitamin or newly prescribed medication), it is recommended you review it with your pharmacist, and your cardiologist/congenital care team. This is especially important if you are taking the blood thinner coumadin

(warfarin). Some vitamins, supplements, and herbs can interfere directly with Coumadin, which may cause bleeding issues. Regularly discuss your medications and any vitamins/herb/supplements you are taking with your cardiologist at each clinic appointment.

16. A normal aortic valve has 3 cusps. With a unicuspid aortic valve, there is fusion of the cusps (the cusps don't separate when the valve is made), which causes the valve to look different when it opens and closes. Regardless of how the valve is made, the timing for replacement is based on a few things. One thing is how well the valve works. The valve may become leaky over time (known as regurgitation), or the valve may begin to get stiffer and have difficulty opening and closing properly (known as stenosis). A second thing is how well the left ventricle is coping with the added work that comes from a valve that is leaking or stiff. The symptoms that may be noticed if an aortic valve isn't working very well include feeling more tired, feeling more short of breath with activity, chest pain with activity, or feeling light headed or faint with activity. You can discuss how well your valve is working, and how your left ventricle is coping, with the work it has to do when you see your cardiologist.

17. Birth control and family planning are both important topics to discuss with your cardiologist and congenital care team. Some forms of birth control are not recommended for certain types of congenital heart disease, so it is important to ask your cardiologist what types of birth control are safe for you. Timing of pregnancy can be important when you have a valve that isn't working well. In some cases, pregnancy can be tolerated prior to the valve being replaced. In other cases, it would be much safer for you and your baby to have the valve replaced prior to becoming pregnant. It is very important to have a discussion about what to you can expect to happen during a pregnancy before becoming pregnant. Having the discussion prior to becoming pregnant helps you to know what to expect during pregnancy and what is most safe for you and your baby.

18. Many patients, including congenital cardiac patients complain of migraines, headaches, and dizzy spells. These symptoms could be related to your heart problem, a neurological problem, your medications, or something total unrelated. If you are having symptoms it is important to bring them to the attention of your family physician or the congenital heart team.

19. Chest congestion at night may be caused by many factors including chest wall mechanics or your heart. If this persists you should call the congenital heart nurse if between visits or discuss with the congenital cardiologist at your next visit.

20. All sports and activities are categorized by the level of intensity (low, medium, high) of dynamic and static component of the exercise required to perform that sport. The dynamic component is defined in terms of the estimated percent of maximal oxygen uptake achieved and results in increasing the cardiac output (how much work does your heart muscle have to do in order to pump blood adequately during exercise). The static component is related to the estimated percent of maximal voluntary contraction reached and results in increasing blood pressure. For example, bowling, cricket, and golf have low dynamic and low static components. Martial arts, boxing, and weight lifting, have moderate to high dynamic and static components. Everyone can exercise. Exercise is good for your physical and psychological well-being. Your congenital heart team can give guidance as to the type of exercise and sporting activities which would be appropriate for you. They can also advise as to what exercise or sport to avoid.

21. Swollen ankles and feet can be related to the heart particularly if it occurs in both ankles and feet. If one ankle or foot is more swollen it may be due to a problem with the veins in the limb. If swollen feet and ankles do not resolve by the morning after a good night's rest in bed, it is important to see your family doctor or call your congenital heart nurse to discuss.

22. No one has a crystal ball to predict what medicine or medical care will be like in the future. Just think how far it has come since the time you were born.

23. If you black out or pass out and regain consciousness within a few seconds you should have someone drive you to the nearest urgent care or emergency department. If you black out and are slow to come around, someone should call 911. The paramedics can do an ecg and assessment on arrival which makes it easier to sort out the issue. Ensure a call is placed to your congenital heart team the next day so that a decision can be made regarding your on-going management.

24. Clubbing is found in many cardiopulmonary disorders. It is a curvature of the nail beds and a swelling of the finger tips. It can also affect the toes. It begins after birth and develops over a period of months. Clubbing in a patient with a congenital heart problem is a sign of an intracardiac shunt with increased pressures in the lungs.

25. Your outpatient appointment should consist of a conversation about life, any concerns or questions you may have, a review of your medications both prescribed and over-the-counter medications, a physical exam, and then a discussion about the plan of care including what tests are required and the timing of your next follow up appointment.

Below is an example of questions that you may wish to ask your congenital heart team:

- What is the name of my heart condition or major surgery?
- Am I cured?
- What is the purpose of each of the medications I take?
- For what symptoms should I seek urgent medical attention?
- What is the best way to contact your office if I have questions between appointments?
- What are the tests that I will have on a regular basis?
- Should I take antibiotics before going to the dentist?
- Should I get a flu shot?
- Am I at risk for palpitations?
- Is it safe for me to get pregnant?
- Are there any exercise limits or concerns that I should know about?
- Is there any special diet that I should follow?
- Do I need to reduce my fluid intake?
- Given my heart condition, is there anything special I should think about when planning for school or a job?
- Is it safe for me to have sex?
- Are there any places or activities I should avoid when I go on vacation?
- Is it okay for me to drive?
- I want to get a piercing or tattoo. Do I need to take any medications first?
- Is it safe for my heart if I drink alcohol? Use street drugs?

26. For the first 6 weeks following AICD implantation it is best not to do any heavy lifting and/or upper body exercises that require repetitive

arm/chest movement as the tissue in that area (lower clavicle/upper pectoral) requires time to heal. It is also normal for this area to be tender for several weeks after device implantation. In theory, repetitive movement can displace device wires/leads or even fracture them so the device may not sense a significant rhythm or deliver a lifesaving shock if required.

Contact sports (wrestling/football/rugby/martial arts) should be avoided as well as rapid acceleration/deceleration activities (bungee jumping/sky diving).

Although the ICD itself is very tough, bruising or breaking the skin over the implant site may lead to the possibility of a "pocket infection". Swimming is permitted when the wound/incision has fully healed.

It is recommended that people with AICDs have regular follow up with their electrophysiologist/defibrillator clinic to ensure optimal functioning of their device.

Cardiac rehab is an excellent option for patients wishing to gain more information on specific activities that are beneficial to improving/maintaining wellness as well as those activities that should be avoided post procedures.

27. Ablations are procedures that "silence" irritable foci in the upper chambers of the heart (atrium) that can cause atrial fibrillation or atrial flutter rhythms. An ablation in itself does not cause the sinus node to slow down. While a slower heart rate can sometimes explain feeling tired/lack of energy, the body normally compensates after several weeks after the procedure.

Heart rates are variable in everyone so each person needs to be evaluated on an individual basis.

Drug therapies are often prescribed in conjunction with the ablation (beta blockers like metoprolol and anti-arrhythmics like amiodarone). These drugs are prescribed to prevent atrial arrhythmias after ablation and are responsible for the decrease in heart rate. One of the most common side effect is feeling tired when these medications are first introduced/or dose increased, however there are multiple factors that can cause low energy besides medications. It is important to follow up with your primary care provider and cardiologist if the lack of energy extends past a few months and/or interferes in your daily living.

28. Grading of the left ventricular is a rough estimate used to describe a patient's left ventricular chamber function as a pump. The grading is assigned after having a transthoracic echocardiogram to see how the ventricle is pumping.

Grade 1 - "Normal Functioning" equivalent to the ability to pump more than 60% of the blood out of the ventricle.

Grade 2 - "Mildly Reduced Functioning" equivalent to the ability to pump 40-60% of the blood out of the ventricle.

Grade 3 - "Moderately Reduced functioning" equivalent to the ability to pump 20-40% of the blood out of the ventricle.

Grade 4 - "Severely Reduced Functioning" equivalent to the ability to pump less than 20% of the blood out of the ventricle.

29. 22q11 microdeletion syndrome is a collection of health features that includes congenital heart problems, learning difficulties, low calcium levels, nasal sounding speech, parathyroid/thyroid problems, seizures/epilepsy, psychiatric illness (bipolar/schizophrenia). Individuals can have other health features and no one person has all features. Like all people with congenital heart disease, each person with 22q11 is unique. The syndrome is a result of a missing portion of genetic information on chromosome 22 which is responsible the body's growth and development. 22q11 microdeletion occurs at a rate of 1 in every 2000 births, it is not routinely tested for, it usually arises from new mutations/genetic changes, and it is not caused by anything the parents did or did not do.

Toronto General Hospital offers a clinic that supports patients with a combined clinic for ACHD & 22q11: The Dalglish Family Hearts and Minds Clinic for adult with 22q11 deletion syndrome. More information is available at [www.22q.ca](http://www.22q.ca).

30. There is no real cut off age for congenital patients requiring heart transplant. For patients age 65 and above who require heart transplant, the patient must be free of other health issues. The oldest patient listed for heart transplant at TGH was 70 years old but he had a clean bill of health. Heart transplantation is consider high risk surgery, and like other high risk surgeries that the older the age of a patient, the more difficult it is for the body recover from the surgery and higher the risk for complications are after the surgery.

<http://www.cbc.ca/news/health/heart-transplant-survival-rates-improving-1.1029059>

31. With the constant improvement in medical and surgical therapies, congenital patients are now living longer with the majority of people reaching adulthood. There is now a greater population of adult congenital patients than there are pediatrics congenital patients. For those with simple congenital lesions that were corrected at an early age, with no late complications/issues, they can experience near normal life expectancies and quality of life.