General Issues for Adults Born with Congenital Heart Disease

Preventive Measures for Healthy Lifestyle

Developing healthy habits that will continue throughout one's life is key for everyone, but especially for adults born with congenital heart disease (CHD). Healthy habits improve one's general well being as well as help prevent heart attack, stroke, high blood pressure, diabetes, and some cancers. Developing cardiovascular fitness can help reduce the extra stress on the heart and lungs from the original heart disease and subsequent surgeries. Recommendations for developing a healthier lifestyle include:

1. Don't smoke tobacco/minimize exposure to second-hand smoke

Smoking limits the amount of oxygen going to the body tissues, increases heart rate and blood pressure, increases the risk of developing blood clots, and damages arteries throughout the body, but especially in the heart and brain. In addition, smoking increases the risk for various lung diseases, of extra concern for persons with cyanotic heart disease.

Second-hand smoke exposure (environmental tobacco smoke) is also a serious health hazard. It increases a non-smoker's risk of death from heart disease and lung cancer and, in children living with an adult who smokes at home, it increases susceptibility to various illnesses.

The addictive effects of nicotine often make it very difficult to quit smoking once one starts; therefore every effort should be made not to start smoking. If an adult with CHD already smokes, the most important thing to do to improve health is to quit. A variety of resources are available from health care professionals, the American Heart Association (AHA), and the American Cancer Society to help stop smoking.

2. Eat a healthy diet

Aim for a diet that is low in fat and cholesterol and high in fiber. This type of diet is recommended by the AHA and other groups to help prevent heart disease and stroke as well as some cancers. For the American public in general, the AHA recommends a diet that limits fat intake to about 30% of total calories (called the AHA Step I Diet). (The average American currently consumes about 40% of total calories from fat.) Get into the habit of reading food labels to find the fat content of food products and go easy on those high in saturated fat or cholesterol.

Limit salt intake. This is of special concern for people with high blood pressure or heart failure.

3. Maintain a healthy weight

Extra weight causes extra work for the heart. Losing weight can help reduce this excess stress and, in addition, help control blood pressure and cholesterol levels, and decrease the chance of developing diabetes. Two recommended methods to estimate body fat are waist circumference and body mass index (BMI). Females with a waist greater than 35 inches and males with a waist greater than 40 inches are considered at greater risk for cardiac and vascular disease. Body mass index (determined from a person's height and weight) categorizes body fat as follows: 18.5-24 kg/m2 = "healthy"; 25-29 kg/m2 = "overweight" (about 10% over ideal); 30 kg/m2 or greater = "obese" (greater than 30# over ideal weight). BMI tables can be found at physician offices, on many web sites and in books about obesity and/or weight loss. One quick calculation for adults is shown below:

FEMALES: ***Baseline = 100 lbs.; add 5 lbs. for every inch over 5 ft.***
Example: 5'4" female = 100 + 20 (additional 4 in. x 5 lbs.) = 120 lbs.

MALES: ***Baseline = 110 lbs.; add 6 lbs. for every inch over 5 ft.***
Example: 6'1" male = 110 + 78 (additional 13 in. x 6 lbs.) = 188 lbs.

4. Exercise regularly

A regular exercise program is encouraged for everyone. While exercise can improve the way one looks and feels, it also has other benefits:

- Helps lower blood pressure and resting heart rate; it can also improve blood flow to the heart.
- Allows the heart to do work with less energy.
- Helps increase HDL or the "good" cholesterol level in the blood.
- Improves flexibility of the muscles and joints, building muscle strength and tone.
- Along with a proper diet, aids in weight loss.
- Relieves stress and tension – helps relax the body and improves sleep.

The AHA recommends 30-60 minutes of aerobic activity (walking, jogging, swimming, etc.) at least 4 times a week for cardiovascular fitness. The need for individualized restrictions should be discussed with your physician. (Refer to next section: Activity/Exercise). Many individuals with CHD had their activity restricted in childhood and may need extra encouragement as adults to exercise on a routine basis.

5. Know your cholesterol

Monitor your cholesterol and know if high cholesterol is in your family history. High blood cholesterol levels, especially LDL-cholesterol (the "bad" cholesterol), are well known to increase one's risk of coronary heart disease. The National Cholesterol Education Program recommends that everyone over 20 years old get their cholesterol checked at least every five years. Cholesterol levels can be lowered by a diet low in fat and cholesterol and by an appropriate exercise program. Some people will require lipid-lowering medication, along with diet and exercise.

6. Know your blood pressure

Monitor your blood pressure and know if high blood pressure is in your family history. A blood pressure reading measures the force of blood as it presses

against the walls of the blood vessels and is made up of two numbers: (1) the top number or systolic blood pressure measures the force while the heart pumps; (2) the bottom number or diastolic blood pressure measures the force while the heart is at rest. High blood pressure or hypertension is defined as a systolic pressure of 140 or greater and/or a diastolic pressure of 90 or greater.

7. If high blood pressure is or has been a problem...

Focus on lifestyle measures to ensure that your blood pressure stays within the normal range. High blood pressure puts extra work on the heart. It is important that you follow your physician's advice on losing weight, cutting down on salt, exercising, taking needed medicines, quitting smoking, and reducing stress. Since high blood pressure often goes undetected, it is important to have it checked periodically.

8. Know your family history of heart disease

It's important to know your family's history of both congenital and acquired (e.g., heart attack, heart failure, angina, etc.) heart disease. Predisposition to a variety of problems tends to run in families. It is important that every individual knows his or her family history as physicians may institute special preventive measures to help those at high risk for acquired heart disease. Some inherited problems may require further family testing.

9. Consult your physician for advice on intake of alcohol

Because drinking alcohol has varying effects on the body, as well as interactions with certain medications, you should consult your physician for specific recommendations. Pregnant women should not drink alcohol in any form as it can cause the baby serious harm, including birth defects. Excessive consumption of alcohol has direct effects on the heart, as well as other important body organs, weakening the heart's muscle and its ability to pump adequately.

10. Avoid illicit drugs

Most of these drugs have very dangerous effects on the heart and should especially be avoided in persons with a pre-existing heart problem. Dangerously

rapid cardiac rhythms, cardiac arrest, heart attack, and abnormalities in blood pressure are some of the effects noted in the cardiovascular system. In addition, intravenous drug use provides another route for bacteria to enter the bloodstream and produce a dangerous infection within the heart called endocarditis.

Activity/Exercise

Although some adults born with CHD may be subjected to varying physical limitations regarding exercise, many will have no restrictions. Restrictions are dependent on the type of CHD, the success of the repair, the current physical condition of the individual and current medications being taken.

Overall, individuals should look for activities that keep the heart and lungs fit as well as ones that are enjoyable to do. For maximum benefit of the heart and lungs, exercise should be rhythmic and aerobic (exercising at an intensity where oxygen is used for energy). Examples of aerobic activities are brisk walking, jogging, recreational cycling, swimming, and low impact aerobics. Higher levels of intensity are associated with anaerobic activity, which is more stressful to the cardiovascular system and should have a cardiologist's approval.

In addition, activities to improve strength and flexibility (e.g., stretching exercises) should be incorporated into one's fitness program. Some individuals with CHD may be restricted from activities that are highly strenuous, i.e., have a large proportion of "isometric" muscle movement. Examples of these activities include heavy weight-lifting or pushing heavy pieces of furniture. Increase in blood pressure, which stresses the heart and the aorta, is greater with isometric exercise than with aerobic activities.

Key factors that are considered in determining the best exercise program for each individual include:

1. What is the intensity of the activity – low, moderate, or high?

For example, brisk walking or social dancing are usually described as "moderate," while running or vigorous biking are usually considered "high" intensity

activities. The appropriate intensity is often determined by the peak heart rate and blood pressure that the individual reaches during a treadmill stress test.

2. What will be the duration & frequency of the activity?
The minimum effective duration of cardiovascular workout is 15-20 minutes, with a goal being 30-60 minutes and a frequency of 3-5 times/week.

3. What will be the risk of body collision during the sport or activity?
This is often an area of concern to children and adults taking anticoagulants, or who have a pacemaker, or who have Marfan's syndrome. Hockey, soccer, and football are examples of activities that are considered high risk for body collision.

4. Will the activity be competitive (usually vigorous, approached with higher intensity), recreational (for pleasure and relaxation, usually more self-limiting), or restricted (prescribed amount)?

5. What kind of training or conditioning is required?

6. What will be the emotional response (or stress) that the participant experiences in anticipation of or during the event?

7. What are the environmental conditions associated with the activity?
For example, individuals need to consider extremely cold or warm temperatures and the effects of high altitude.

Every adult with a history of CHD should seek approval and recommendations from his or her cardiologist. Most will need to undergo a basic stress test at intervals to evaluate the heart's response to exercise – especially if there has been a recent change in health and/or a new exercise program is being undertaken. Occasionally, more sophisticated stress testing may be recommended.

Preventing Endocarditis

(See Family Living chapter for more on SBE Prophylaxis.)

Dental Care

As in childhood, good dental hygiene habits should be maintained to prevent bacteria from entering the bloodstream and causing a life-threatening heart infection. Dental visits for cleaning and checkups are recommended at least every six months. Dentists should be kept up-to-date of any changes in your heart condition and/or medications, especially blood thinners, such as Coumadin.

Most individuals with a congenital heart defect have been advised to take antibiotics before dental procedures; they should continue this practice even after surgical repair unless counseled otherwise by their cardiologists. Recommendations for antibiotic use (issued jointly by the American Heart Association and the American Dental Association) change from time to time – if any questions arise, your cardiologist should always be contacted for clarification. Carry an AHA wallet card, usually available at the cardiologist's office, at all times.

In addition to routine checkups, adults with heart problems should continue brushing with a soft toothbrush twice daily, once in the morning and again before going to bed. You should also floss carefully once a day, taking care not to traumatize the gums. Check with your dentist or physician if your gums bleed excessively, especially if you are taking blood thinners.

Skin Care

It is important to remember that the skin provides a "barrier" against potentially serious infections – an especially important barrier if you have CHD. Anything that could break this barrier should be avoided, such as picking at cuticles, scabs, or pimples. A dermatologist should be consulted for possible antibiotic treatment of severe acne.

Questions regarding tattoos, body piercing, or electrolysis should be discussed

with your cardiologist. If it is approved, prophylactic antibiotics may be advised. Before the procedure, the skin should be thoroughly washed; after the procedure, any sign of redness, swelling or discharge should be noted and reported to one's primary physician immediately!

Regularly Established Plan for Follow-up of Heart Problem

It is important to develop a plan for general health maintenance and follow-up of CHD as teens/young adults leave home and/or the care of their pediatrician. It is often at this point that many adults do not continue with follow-up medical care. Inadequate health care coverage as an adult may be a contributing factor. (See section on Insurability.) Women may follow up with their obstetrician/gynecologist, who may, in turn, refer them to an adult cardiologist, especially in the case of pregnancy. (See section on Reproductive Issues.)

Follow-up care includes a physical examination with intermittent echocardiograms and/or exercise stress tests by a cardiologist who specializes in the care of patients with CHD. The visit should include time for discussion about the various topics introduced in this chapter, e.g., recommendations regarding exercise, insurance issues, problems with employment, sexual concerns, family planning issues, and clarifying information about heart problems, medications, etc.

Any time individuals change residence and/or change cardiologists, they should obtain a copy of their medical records to take with them to the new appointment. This should include catheterizations, operations, and recent echocardiograms and ECG's (electrocardiograms).

Hospitalization and/or ER Visit

Adults with CHD may need to be seen in a hospital, clinic, doctor's office, or emergency room in which the staff may be unfamiliar with the care of congenital heart problems. An unexpected hospitalization, an emergency non-cardiac surgery or treatment of trauma can be much riskier for the CHD patient. It is your responsibility to be knowledgeable about your heart condition. Carry an abbreviated medical history, including dates and types of surgeries, a list of current medications (with

dose and when taken), the need for antibiotic prophylaxis, and the name and telephone number of the cardiologist whenever possible. A MedicAlert bracelet or neck pendant should also be considered for specific problems and telephone numbers.

In the event of a non-cardiac procedure, CHD patients should first receive clearance from their cardiologists. Most people will tolerate non-cardiac procedures well. Certain individuals with higher risk of cardiac complication (e.g., patients with cyanotic heart problems, heart failure, or heart rhythm abnormalities) will require careful monitoring during the procedure and special considerations when the anesthesia is administered. This may mean having the procedure done at a specialized center and/or with specific recommendations from a congenital heart specialist. In addition, special precautions may need to be taken before or during the procedure if the person has a pacemaker or implantable defibrillator. The device may need to be double-checked after the procedure to make sure that the settings were not affected by any electrical interference. After surgery, getting out of bed and walking as early as possible will be especially important to prevent blood clots from developing.

Travel Considerations

The need to restrict travel depends on the type of CHD and the individual's current overall health status. When selecting a destination, the following factors should be considered:

1. Access to emergency medical care. Inquire where and what type of emergency care is available and where a person would be taken for advanced care and hospitalization. A letter with current medical information should be carried at all times. (See section on Hospitalization.)

2. Physical stress associated with the itinerary. Some destinations require much walking and climbing and/or very long, tiring days. Whenever possible, modify your schedule to lessen unnecessary physical stress.

3. The extremes of altitude and climate, especially high altitudes (e.g., ski trips) and extreme heat or cold:

• High altitude: It may be worthwhile to take the first few days of the trip to get acclimated to the altitude – the "thinner air" and less available oxygen – before starting with rigorous physical activity/touring.

• Extreme heat: In this situation it is important to keep activity at a "reasonable" minimum and drink enough fluids to stay hydrated. Water is the fluid of choice and should be kept available at all times. Alcohol should be avoided because it can, among other things, cause further loss of body fluid.

• Extreme cold: Out-of-doors activity may need to be restricted in this type of climate (including shoveling snow). Cold temperatures cause blood vessels to constrict, thus forcing the heart to work harder to get blood through the narrower vessels.

For the various situations encountered when traveling, adults with CHD should be prudent and use common sense, but not live in fear that they should needlessly restrict their lifestyle. Any questions or concerns should be directed to your cardiologist.

Patients with pulmonary hypertension, cyanotic heart disease, and severe heart failure are at risk at high altitude and during air travel. They should not travel in mountainous areas significantly higher than 5000 feet (e.g., Denver, Mexico City). When flying, supplemental oxygen may be required. The airlines need to be notified of this special request in advance – an extra charge will be incurred. When traveling by air, especially on long flights, individuals should be encouraged to frequently get up and move about the cabin. This keeps blood from pooling in the legs and feet and forming blood clots.

Lifestyle Issues

Employability

One of the important life decisions for adults born with CHD is choice of career path. Start talking about careers early on, beginning in junior and senior high schools. Choices should be realistic for one's mental, physical, and social or personal abilities.

Although most individuals with CHD enter the workforce with unlimited restrictions, many young adults with complex defects develop physical limitations as they get older. When evaluating career opportunities, the major focus should be to look at an area where a person can potentially work through to retirement, even with increasing physical limitations. Discuss questions and concerns with the cardiologist. The document *Occupational Recommendations for Young Patients with Heart Disease* (AHA, 1986) may provide additional information for those seeking advice. State-run vocational rehabilitation services are available and provide vocational counseling and training for those identified with either a physical or mental disability.

Adults with CHD may experience workplace discrimination once they pursue a job. Discrimination may be felt to varying degrees and may be attributed to uncertainty about physical ability, fear of absenteeism due to illness or doctors' appointments, and the rising costs of providing insurance benefits. If you feel that you are being treated unfairly by your employer because of CHD, you may have rights under the ADA *(Americans with Disabilities Act)* and various state laws. However, disability discrimination involves a complicated analysis of the medical condition, as well as the work circumstances. Be sure to seek competent legal advice before initiating a complaint or legal action to determine the best approach for your particular problem. The EEOC (Equal Employment Opportunity Commission) does accept these charges and will assist an individual in writing the charge, but that does not guarantee that the EEOC will act on the charge and prosecute the claim. Prompt attention to the problem at work when it starts is essential, because delay can result in denial of legal redress or cause the problems to persist at work and get worse.

A list of other federal government resources for which persons with disabilities may be eligible can be obtained from the U.S. Department of Education.

Insurability

Health insurance coverage often becomes an issue in late teens or early 20's. Before this time, a child with CHD will be covered on his or her parent's policy or is covered through a state-funded health program. The best way to obtain coverage is through one's job or the job of a family member. The Health Insurance Portability

and Accountability Act of 1997 eliminated the 12-month waiting period often imposed when switching health plans. Now this waiting period only applies to those with a pre-existing condition and no health insurance for the previous 12 months (e.g., those coming out from under parent's policy). Young adults can often work around this by planning needed follow-up care before leaving their parent's policy or after the 12-month wait. When changing jobs, evaluate insurance options and try to avoid letting coverage lapse. Continuing coverage under COBRA (Combined Omnibus Budget Reconciliation Act) during extended times of unemployment should be pursued before leaving a current employer.

The following points should be considered when obtaining insurance for health care:

- Seek employment with a large company (likely to offer generous health benefit packages).
- Check for restrictions (e.g., special waiting periods).
- Look for ways to cut coverage (increase deductibles, etc.).
- Check structure of plan. (Some companies are self-insured. Pay special attention to how the plans are structured and administered.)
- Get dental coverage if possible.
- See if the plan handles prescription drugs.
- Examine if there would be difficulty obtaining referrals for specialist care (e.g., cardiologist with adult congenital heart disease focus).
- Request that a medical person from the insurance company review your case, as nonmedical insurance personnel will more often reject your insurance inquiry due to lack of medical knowledge.

Some states have enacted legislation creating a risk-sharing or reinsurance pooling for otherwise "medically uninsurable" individuals. Unfortunately, these programs also carry higher premiums. Because eligibility varies from state to state, specific information can be obtained by contacting each state's insurance board.

Adults who are unemployed or who have insufficient income may qualify for coverage under Medicaid. This jointly-funded Federal-State health insurance program includes coverage for physician visits and hospitalizations. Application is usually made at the state Department of Human Services office. If the cost of medications becomes a hardship, many drug companies have programs for the indigent which can

be pursued through your physician's office or through a very comprehensive listing at the website, www.needymeds.com.

Unfortunately, there are still many individuals unable to qualify for Medicaid who are among the working poor and lower-middle class (often seasonal workers, short-term employment at low wages). These people usually have no health insurance and find long-term health care difficult to obtain. They may want to explore county or state medical providers or local clinics funded by special grants – including those also offering dental care. Ultimately, these individuals should consider vocational counseling and/or job training and search for employment in areas with better insurance coverage and more stable employment.

Life Insurance

Life insurance is desirable as a means of establishing financial independence for you and your family. Although more liberal coverage is available today, adults with congenital heart disease remain underinsured, compared with the general population. Not enough is known about the lifespan of individuals who had their defects repaired 20-30 years ago. Therefore insurance companies have very old information on which to base the insurability risk for certain congenital conditions. Individuals having difficulty obtaining life insurance may want to pursue some of the following options:

- If turned down as a child, try at a later time, especially after 16 years of age.
- Seek assistance from your personal physician to provide supportive information, interpret test results, etc.
- Try large well-known companies; sign up when starting a new job.
- Shop around; try an independent insurance agent who usually works with several companies with different restrictions.
- Consider group term life insurance.
- Try to build equity other than through life insurance.

Request that a medical person from the insurance company review your case, as nonmedical insurance personnel will more often reject your insurance inquiry due to lack of medical knowledge.

Psychosocial Issues

Most young people who have grown up with the diagnosis of CHD and the associated stressful experiences (e.g., major surgery, multiple doctor visits, restricted physical activities) appear to have adjusted well and have few behavioral issues as they move into adulthood. In fact, these individuals often show an amazing ability to cope with stress later on in life, attributed to their encounters with stressful experiences in the earlier years.

On the other hand, because of problems experienced in childhood, individuals with CHD may develop some of the following problems in adjustment as they move into their adult years:

Developing non-compliant, destructive behaviors:
Some adolescents and young adults don't accept their illness or minimize its importance up to the point of feeling incapable of experiencing any harm. They stop taking their medications or seeing their physician for follow-up. Some get involved with destructive behaviors, like alcohol or drugs. The difficult task of getting to the root of these behaviors is necessary to prevent persons from doing permanent harm to themselves and putting additional stress on their heart. Education regarding abusive behavior should begin very early.

Difficulty in developing independence:
Some individuals with CHD remain in a very passive, dependent role as they become adults, relinquishing the adult role to others (e.g., parents, physician, or spouse). Often this problem is associated with pampering and overprotection during childhood. Along with fostering independence in general, parents must assure that adolescents/young adults start taking responsibility for their own healthcare—knowing all about their congenital problem, past surgeries and hospitalizations, and medications. (See General Health Care Issues: Plan for Follow-up Care & Hospitalization and/or ER Visit). As individuals with CHD move through the teen years, they should start visiting with the doctor alone and be assisted in transitioning to adult physicians.

Sexual/marital concerns:

Concerns often arise as young people with CHD begin dating.They may not know when to disclose that they have a "heart problem," and perhaps hesitate saying anything at all for fear of rejection. There is typically more expressed concern over sexual issues than with other chronic diseases – by both young men and women – such as fear of performance or of dying in bed. CHD can be accompanied by problems of low esteem, resulting in a need to limit romantic aspirations or seek relationships with people who are "caretakers." Additional concerns arising with marriage include feelings of uncertainty over the financial provider role, and for women, their childbearing ability. (See section on Reproductive Issues). Ask your cardiologist about sexual issues, including sexual orientation. It is important to get needed information and referral to appropriate resources.

Workplace issues:

Within the workplace, CHD adults may face real or perceived disadvantages in the job market and with job discrimination. (See section on Employability).

Accepting one's illness as an adult:

Depending on the diagnosis, some people with CHD may be faced with new limitations or changes in their condition as they enter the adult years, forcing them to take a hard look at their illness and life goals. Support from family and friends can be extremely important.

Anxiety and depression:

Both anxiety and depression appear more frequently in adults with CHD than in the general population. Both can be treated if recognized and appropriate help is sought. Bring these issues up for discussion with your congenital heart physician. The cardiologist may refer you to a psychologist or psychiatrist, ideally one who has a close working relationship with the cardiologist to make consultation easier for medications and other aspects of care.

Family and friends can help with behavioral issues. Your congenital heart physician can also help. Do not be afraid to bring these issues up at any doctor's visit.

Adults with CHD may also find it helpful to locate others with like issues for support and discussion. Most major cities have support groups for adults with congenital heart problems and several web sites run by adults with similar problems can be found on the internet.

Reproductive Issues

Menarche & Menstruation

In general, young women with CHD have their first menstrual period (the ability to ovulate and conceive) later than the "average" age of 12.3 years in the general population. Girls with acyanotic (pink) heart defects begin their periods slightly later than the general population, but then tend to have fairly normal menstrual patterns. Girls with cyanotic (blue) heart problems begin their menstrual periods significantly later and tend to experience more irregularities, such as break-through bleeding and missed periods.

If a woman with CHD needs to be started on any medications to regulate her period, she should first consult with her cardiologist (congenital heart disease doctor).

Birth Control

Discussions on birth control and any risk from pregnancy should be initiated in early adolescence, especially for women in whom pregnancy could cause major cardiac problems or be life threatening. (See section on Pregnancy.)

The appropriate type of birth control for women born with CHD varies widely, depending on the type of heart problem and its repair:

- ***Barrier methods*** (e.g., sponge, diaphragm, condom) – are about 80% reliable if used correctly with spermicide; this is improved if the male uses a condom at the same time that the female uses a barrier. Barrier methods are very safe and are often recommended for the woman with CHD.

- ***Oral contraceptives*** (especially estrogen/progestin combination) – are very effective (97% reliable) but may be problematic for some women as they are associated with blood pressure problems, salt and water retention, and blood clotting risks.

• ***Long-acting intradermal preparations*** (such as Norplant - methylprogestin) – are highly effective as above. This type of contraceptive may be an acceptable alternative if an oral contraceptive is not recommended. It may be indicated for the woman who finds it difficult to take medications regularly. Prophylactic antibiotics may be necessary when the Norplant is implanted.

• ***Intrauterine device (IUD)*** – can be complicated by local pelvic infections and subsequent generalized infections and is therefore not recommended for any woman at risk for bacterial endocarditis (infections of the heart).

• ***Sterilization*** (male vasectomy or female tubal ligation) -- may be recommended when pregnancy is too dangerous for the woman's health.

Family Planning/Genetic Counseling

Both men and women with CHD who are considering starting a family should obtain information about the genetic transmission of CHD well in advance of pregnancy. The risk for genetic transmission overall is very low, but is still higher than in the general population.

The person with CHD and his/her spouse may be referred for genetic counseling for additional guidance and evaluation. An ultrasound or echocardiogram of the fetal heart is recommended usually between the 16th and the 20th week of pregnancy to determine if complex congenital heart disease is present. Ultrasound results can offer reassurance to the parents and/or help determine special needs before or at the time of delivery.

Pregnancy

Many CHD patients tolerate pregnancy well, although pregnancy puts an increased workload on the cardiovascular system. It is very important to discuss this issue with your heart physician ***before*** becoming pregnant. The potential risks for the woman during pregnancy are determined by the nature of the defect, result of the correction, ***and*** her overall physical status. Additional heart tests are sometimes needed to evaluate the heart's ability to withstand the extra work of pregnancy. For women

planning a pregnancy, certain surgeries may also be done sooner or later than normally planned. In addition, because certain medications can be harmful to the fetus, the physician may need to change some of the medications before conception. Folic acid should be taken daily whenever pregnancy may occur.

Many women with CHD will have a normal pregnancy and delivery. Some women at moderate risk should be followed in a high-risk pregnancy program with her cardiologist, a high-risk obstetrician and an anesthesiologist working together to ensure a safe delivery. Special considerations throughout labor and delivery may be needed, including extra monitoring, additional rest and special medications.

Spontaneous vaginal delivery is usually permitted for women with repaired CHD; Cesarean section is recommended for special obstetrical situations. After delivery, the changes in the woman's body take six to twelve weeks to resolve. The cardiologist may recommend an echocardiogram after this time to assure that the heart has returned to its pre-pregnancy size and function.

For some women with certain congenital heart defects, pregnancy may ***not*** be advised. This is true for women with a cyanotic defect, pulmonary hypertension, severe heart failure, or fragile blood vessels (e.g., with Marfan's syndrome). In this same group, there may be complications for the fetus also. Babies born to cyanotic mothers are often premature and small for their age.

Menopause

Although many women born with CHD are now in their forties and fifties, there is no specific information available about the effects of congenital heart disease or its treatment on this time in a woman's life. As with the general population, women with CHD should be advised by their physician about hormone replacement therapy.