



COMMONWEALTH of VIRGINIA

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Office of Integrated Health Supports Network

Heart Disease in Individuals with Intellectual and Developmental Disabilities Health & Safety Alert

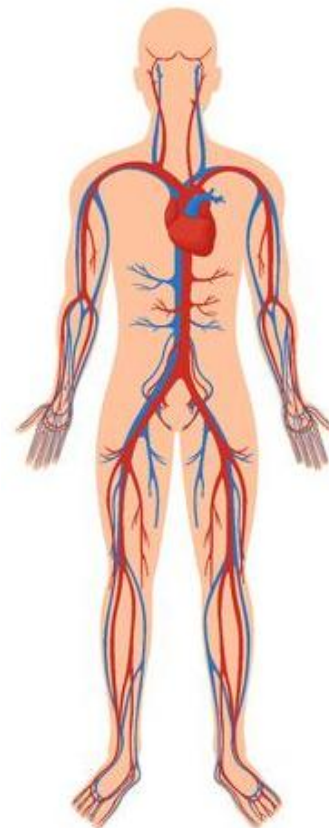
Introduction

The heart (cardio), and blood vessels (vascular) make up the body's cardiovascular system. The blood vessels are made up of arteries, veins, and capillaries. The heart pumps oxygen-rich blood through the blood vessels to the body. The arteries carry the blood from the heart to the body. Veins return deoxygenated blood to the heart, and capillaries connect the two at the cellular level (8)(30).

Cardiovascular conditions are referred to as "*Heart Disease*". Heart disease is a general term for conditions that affect the heart's structure and function (21).

Types of heart disease can include:

- Congenital heart defects, which are heart conditions a person is born with.
- Coronary artery disease (CAD), sometimes referred to as coronary heart disease (CHD), is the narrowing of the blood vessels caused by plaque buildup.
- Hypertension (high blood pressure) and Hyperlipidemia (high cholesterol) damage arteries and the heart over time, often with no noticeable signs until significant harm occurs.
- Arrhythmias (e.g., Atrial fibrillation or AFib), which means an irregular heartbeat, pulse, or heart rhythm.
- Cardiomyopathy, which is a thickening and weakening of the heart muscle itself.
- Congestive heart failure, a condition that occurs when the heart becomes too weakened to pump blood efficiently, causing fluid buildup in the lungs (pulmonary edema) and swelling throughout the body (edema).
- Heart valve disease, which disrupts the flow of blood when one or more of the heart's four valves don't work properly (20).



Some types of heart disease can go undetected in an individual for years, mimicking other illnesses or presenting with vague symptoms such as fatigue, breathlessness, crackling breath sounds, jaw pain, a persistent cough, and repetitive infections (e.g., pneumonia), making it difficult to detect until a major event occurs (6).

Heart Disease and Individuals with Intellectual and Developmental Disabilities (IDD)

Individuals with IDD are living longer today than ever before, and as a result, they are experiencing more age-related health conditions such as heart disease (18)(11).

Individuals with IDD have a much higher risk of heart disease than the general population due in part to:

- Genetic syndromes.
- Metabolic syndromes.
- Frequent use of prescription psychotropic drugs.
- Higher occurrences of secondary chronic conditions such as diabetes, kidney disease, and mental health issues.
- A sedentary lifestyle (16)(11).

There is an element of “*does the risk outweigh the benefit*” when it comes to the diagnostic tests and procedures required for some heart disease diagnoses. In addition, the individual’s quality of life may be negatively affected by the side effects associated with some treatment regimens.

Sometimes, treating the condition that may result in heart disease becomes a secondary priority to other, more urgent health concerns. These complicating factors often result in a lack of heart disease-related diagnostic tests, procedures, and treatments being ordered/prescribed for individuals with IDD (11).

A team approach is required to determine what possible advantages there might be in both the diagnostic tests and management of heart disease for individuals with IDD. The team should include:

- The individual.
- Their Primary care provider (PCP).
- Other healthcare specialists.
- Family members.
- Support coordinators.
- Community support persons (13)(11).

Diagnosing heart disease in individuals with IDD is a challenging prospect for PCPs for

- Heart disease symptoms may present differently in individuals with IDD.
- Individuals with IDD sometimes have difficulty understanding abstract concepts such as “chest pain”, “chest tightness”, “shortness of breath”, etc. Due to this, they may deny having those symptoms even when they have experienced them.
- Other individuals may be better able to recognize the symptoms they are experiencing but may be unable to explain them in a way their physician can understand.
- Some individuals may be unable or unwilling to interact with healthcare professionals due to behavioral issues, previous trauma, or mental health diagnoses.
- Other individuals may be non-verbal (unable to communicate verbally) and have such severe and profound cognitive deficits that they are not able to communicate using other methods (e.g., communication boards, assistive technology, etc.).
- Individuals might have physical limitations (contractures, obesity, paraplegia, arthritis, etc.) that negatively impact the PCP's ability to complete an accurate, comprehensive physical assessment (11).

Coronary artery disease most often occurs among individuals with IDD who are over 40 years of age, use tobacco products, have low physical activity levels, are overweight or obese, and those who take antipsychotic medications (23)(13)(11).

- Individuals with mild IDD who live more independently in the community and make many of their own lifestyle decisions concerning diet and activities have a higher likelihood of being diagnosed with heart disease due to unhealthy choices (18)(32)(11).
- From adolescence through adulthood, individuals with IDD are predisposed to hypertension due to an increasingly sedentary lifestyle, putting them at increased risk for heart disease and sudden cardiac death (23)(27)(15).
- Individuals with IDD encounter several barriers to improving their physical activity level to include physical ability, transportation issues, a lack of awareness of activity options available in the community, financial limitations of affordability to participate, lack of policies for involvement in community athletic activities by residential and day program service providers along with negative attitudes from family members and support staff (14).
- Current research reports that 35% or more of the IDD population falls into the category of either being overweight or obese, which is partly due to genetic syndromes and the side effects of prescribed psychotropic medications (32)(11)(19).

All individuals with any type of genetic syndrome is at higher risk of congenital heart defect at birth such as those with Downs syndrome, Turner syndrome; 22q11 deletion syndrome; Williams syndrome; Noonan syndrome (17)(9)(19).

- Cardiovascular disease is the most common healthcare complication that individuals with Downs syndrome experience, while individuals with Noonan syndrome experience high rates of cardiomyopathies (17)(9)(19).
- Both individuals with Downs and Noonan syndrome are known to experience more heart arrhythmias such as atrial fibrillation, hypertension, and low blood pressure (17)(9)(19).
- Individuals diagnosed with Turner syndrome frequently have heart valve defects and atrial narrowing. While individuals with Williams syndrome are more likely to suffer from a form of vascular narrowing (stenosis) affecting the main arteries of the heart. All types of heart disease result in an increased risk of hypertension (5)(1).
- Individuals diagnosed with genetic syndromes such as Williams syndrome, Pader-Willi syndrome, and Down syndrome experience increased obesity, congenital heart disease, diabetes mellitus, hypertension, venous insufficiency, hypothyroidism, and hyperlipidemia, putting them at increased risk for sudden cardiac death (5)(1).

Research indicates that 25% or more of individuals in the IDD population experience metabolic syndrome. Metabolic syndrome is a combination of characteristics that increase the risk of heart disease, stroke, and heart attack, such as:

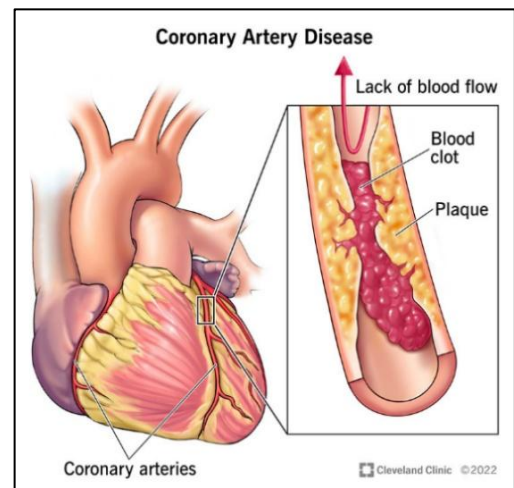
- Carrying a large amount of body weight around the waist.
- High blood pressure (hypertension).
- High levels of cholesterol and triglycerides.
- High blood sugar levels (hyperglycemia) (27).

Coronary Artery Disease (CAD)

Coronary artery disease (CAD) is the most common type of heart disease and is generally referred to as heart disease (24)(7). Heart disease is the leading cause of death in the general population in the U.S. and worldwide (23)(24)(7).

CAD is a type of heart disease that occurs when the arteries of the heart cannot deliver enough oxygen-rich blood to the heart muscle due to narrowing from the buildup of deposits called plaque (10)(20).

Plaque buildup develops from fats, cholesterol, and other substances in and on the artery walls. This buildup of plaque in the arteries is called atherosclerosis. Atherosclerosis reduces the blood flow to the heart and other parts of the body (20)(24).



CAD can be either chronic, referred to as stable ischemic heart disease, or acute, referred to as acute coronary syndrome (10)(20).

Acute coronary syndrome is a medical emergency; known as the silent killer because a person might not notice anything is wrong until the blood flow to the heart is blocked by plaque that has ruptured in the coronary artery. The blood clot blocks the blood flow, which causes a myocardial infarction (MI), commonly referred to as a heart attack (10)(20)(24).

Stable ischemic heart disease occurs when the arteries gradually narrow over time with plaque. The body receives less oxygen-rich blood, which may cause an individual to struggle mentally and physically to adjust on a day-to-day basis (10).

Symptoms of Coronary Artery Disease

Sometimes, the first symptom of CAD an individual has is a heart attack, or myocardial infarction (MI). A heart attack is a life-threatening emergency that requires an immediate call to 911 and cardiopulmonary resuscitation (CPR) to save an individual's life and stop major organ damage.

Every minute the heart goes without blood flow, it causes permanent damage to the brain and body. If lifesaving care such as CPR is not started right away, a heart attack will result in death.

Heart attacks can have many symptoms. Symptoms most people describe include:

- Chest pain (angina).
- Pain in the neck, jaw, throat, upper belly or back.
- Shortness of breath or trouble breathing.
- Trouble sleeping (insomnia).
- Nausea or stomach discomfort.
- Heart palpitations.
- Anxiety or a feeling of “impending doom”.
- Feeling lightheaded, dizzy or passing out.

Women have reported different symptoms than men when experiencing a heart attack. Men express having chest pain, tightness or pressure. Women say they have feelings of indigestion, shortness of breath, fatigue and insomnia which starts before the heart attack happens. They also have nausea and vomiting or deferred pain in their back, shoulders, neck, arms or abdomen (10)(20).

Some individuals may not have any symptoms of CAD for many years. It can take a long time for plaque to build up in the arteries, and for the narrowing to occur.

Mild symptoms like the heart beating harder and faster to deliver oxygen-rich blood to the body and shortness of breath (dyspnea) during light physical activity can be the first signs of CAD (10).

The most common symptom of CAD is called stable angina, which is temporary chest pain, chest tightness, chest pressure and chest discomfort that comes and goes, typically during physical activity or emotionally distress which goes away when able to rest and relax or with the administration of nitroglycerin (10).

Risk Factors of Coronary Artery Disease

The possibility of developing CAD can be divided into two categories, modifiable and non-modifiable risk factors (25)(24).

Non-modifiable risk factors include:

- Gender - Men are more predisposed to CAD than women.
- Age - Being older than 45 years if male, and 55 years if female.
- Family history/Genetics - Having a biological family member with heart disease, especially a father or brother with a diagnosis of CAD before age 55 or mother or sister before age 65 (25)(24).

Modifiable risk factors include:

- High blood pressure (hypertension), which is defined by healthcare providers as a top number (systolic) of 130 mmHg or higher, or a bottom number (diastolic) of 80 mmHg or higher (25)(10).
- Smoking tobacco products can injure blood vessels, promote inflammation, raise bad cholesterol (LDL), lower good cholesterol (HDL), and increase clotting factors, making the heart work harder and increasing stroke and heart attack risk.
- Obesity which is a body mass index (BMI) higher than 25, makes the heart work harder, increasing inflammation, damaging blood vessels, and disrupting metabolism, leading to high blood pressure, high cholesterol, Type 2 diabetes, and sleep apnea, putting undue strain on the heart, causing it to enlarge, stiffen, and become prone to blockages, heart failure, and arrhythmias (4)(25).
- High lipid levels & triglycerides. High levels of LDL (bad cholesterol), low levels of HDL (good cholesterol) and high triglycerides contributes to plaque buildup which causes the narrowing of arteries resulting in CAD.
- A sedentary lifestyle can be defined as sitting daily for 4 to 6 more hours or less than 5,000 steps a day. A routine with a lot of sitting and lying down, with very little or no exercise increases CAD risk by slowing metabolism, reducing circulation, and weakening the heart (15)(25)(22).

- Chronic healthcare conditions like anemia, autoimmune diseases, kidney disease, diabetes, etc., can damage blood vessels, cause inflammation, and straining the heart leading to increase CAD risk.
- Sleep disorders like sleep apnea, and snoring, can lead to elevated blood pressure and cardiac arrest (10)(24).
- Dental health. The same germs found to cause plaque buildup on the teeth and gum disease in the mouth have been connected to cardiovascular disease (2).

Complications

Possible complications of heart disease are:

- Heart failure. This is one of the most common complications of heart disease. The heart can't pump enough blood to meet the body's needs.
- Heart attack. A heart attack can happen if a piece of plaque in an artery or a blood clot moves to the heart which blocks blood flow.
- Stroke. Heart disease can lead to an ischemic stroke. This type of stroke happens when the arteries to the brain are narrowed or blocked. Too little blood reaches the brain.
- Aneurysm. An aneurysm is a bulge or ballooned section in the wall of an artery. If an aneurysm bursts, it can cause life-threatening internal bleeding.
- Peripheral artery disease. Occurs in the arms or legs, usually first noticeable in the legs, and is when the blood supply is greatly reduced. The symptoms include leg pain when walking, called claudication. Atherosclerosis can lead to peripheral artery disease.
- Sudden cardiac arrest or myocardial infarction (MI). Sudden cardiac arrest is the sudden loss of heart activity, breathing and consciousness. It's usually due to a problem with the heart's electrical system. Sudden cardiac arrest is a medical emergency. If not treated immediately, it results in sudden cardiac death (20).

Heart Disease Symptoms Caused By Arrhythmias

When the heartbeat, or heart rhythm, is too fast, too slow or irregular, this is called arrhythmias. Heart arrhythmia symptoms can include:

- Chest pain or discomfort.
- Dizziness.
- Fainting or almost fainting.
- Fluttering in the chest.
- Lightheadedness.

- Racing heartbeat.
- Shortness of breath.
- Slow heartbeat (20).

Heart Disease Symptoms Caused By Congenital Heart Defects

A congenital heart defect is a heart condition present at birth. Serious congenital heart defects usually are noticed soon after birth. Congenital heart defect symptoms in children could include:

- Blue or gray skin. Depending on skin color, these changes may be easier or harder to see.
- Swelling in the legs, belly area or areas around the eyes.
- In an infant, shortness of breath during feedings, leading to poor weight gain.

Some congenital heart defects may not be found until later in life during adulthood. Symptoms may include:

- Getting very short of breath during exercise or activity.
- Easily tiring during exercise or activity.
- Swelling of the hands, ankles or feet (20).

Heart Disease Symptoms Caused By Cardiomyopathy

Initially heart muscle disease (cardiomyopathy) may not cause noticeable symptoms. As the disease progressively worsens symptoms may include:

- Dizziness, lightheadedness and fainting.
- Fatigue.
- Feeling short of breath during activity or at rest.
- Feeling short of breath at night when trying to sleep or waking up short of breath.
- Rapid, pounding or fluttering heartbeats.
- Swollen legs, ankles or feet (20).

Heart Disease Symptoms Caused By Heart Valve Disease

The heart has four chambers with four valves dividing them. The valves open and close to circulate blood through the heart and lungs. The heart valve can be damaged by a variety of factors. Heart valve damage typically falls into three main categories: stenosis (narrowing), regurgitation (leaking or backflow), and atresia (a valve with no opening). Symptoms of heart valve disease depend on which heart valve isn't working correctly.

Symptoms may include:

- Chest Pain/Pressure: Can occur with exertion or tightness.
- Dizziness/Fainting: Feeling light-headed or actually passing out.
- Fatigue & Weakness: Feeling unusually tired or having decreased stamina.
- Palpitations: An irregular, fluttering, or rapid heartbeat.
- Rapid Weight Gain: Another sign of fluid retention.
- Swelling (Edema): In the ankles, feet, legs, or abdomen due to fluid buildup (20).
- Heart Murmur: A whooshing or swishing sound heard during a heartbeat, indicating abnormal blood flow.
- Pulsations: Feeling throbbing in the neck or abdomen.

Care Considerations

While many risk factors of heart disease cannot be changed, many of them can be modified. Diet and activity are areas where improvements can be easily made.

- A healthy, balanced diet has been shown to reduce the risk of heart disease by as much as 50% (31). The U.S. Department of Agriculture (USDA) My Plate.gov recommends an individual's daily nutritional intake include 3 servings of vegetables and 2 servings of fruit (26).
- More than half of the food consumed worldwide is ultra-processed food. Research has directly connected the consumption of ultra-processed foods with obesity, metabolic syndrome, heart disease, type 2 diabetes, cancer and depression (31).
- Common Examples of Ultra-Processed Foods:
 - Beverages: Sodas, energy drinks, sweetened juices, flavored milks, sports drinks, powdered drink mixes.
 - Snacks & Sweets: Chips, pretzels, cookies, candy bars, ice cream, pastries, packaged cakes, and chocolate.
 - Breakfast Foods: Sugary cereals, flavored yogurts, instant oatmeal, frozen waffles, toaster pastries, breakfast bars.
 - Processed Meats: Hot dogs, sausages, chicken nuggets, fish sticks, deli meats, jerky, ham.
 - Convenience & Frozen Meals: Frozen pizzas, TV dinners, instant noodles, boxed macaroni & cheese, pre-made pies, chicken tenders.
 - Baking & Mixes: Cake mixes, brownie mixes, biscuit mixes, packaged bread, and buns.
 - Spreads & Others: Margarine, some processed cheeses, energy/protein shakes, meal replacement powders, many sauces.

- Health insurance companies offer nutrition consultation, and Virginia Medicaid generally does cover nutritional programs, like Foodsmart for meal planning, dietitian counseling, and Medical Nutrition Therapy (MNT) for individuals as a preventive service to address chronic health conditions such as diabetes, obesity, and heart disease (12).
 - Check with the individual’s insurance provider and/or Virginia Medicaid provider to verify what type of nutritional services are available.
- Elbers et al. (2022) reported that approximately 10% or less of the IDD population had activity levels that would benefit their overall health to combat chronic health conditions like heart disease (13).
- The “*World Health Organization (WHO) Guidelines on physical activity and sedentary behaviors*” is written for all populations and age groups ranging from 5 years to 65 years and older, states that physical activity for individuals with impaired cognitive functioning improves physical performance during activities of daily living, balance, and coordination along with benefiting cognitive functioning which positively improve overall quality of life.

Recommendations include:

- Doing *some* physical activity is better than doing none.
- Individuals with IDD should start by doing small amounts of physical activity, and gradually increase the frequency, intensity, and duration over time.
- There are no major risks to adults living with disabilities engaging in physical activity when it is appropriate to the individual’s current activity level, health status, and physical functioning. The health benefits accumulate to outweigh the risks.
- Individuals with IDD may need to consult with their PCP, or other healthcare professional, or other physical activity and disability specialist to help determine the type and amount of activity appropriate for them (29).
- The WHO activity guidelines recommended on average between 150 and 300 minutes per week of moderate intensity physical activity, such as:
 - Briskly walking
 - Swimming
 - Sweeping, mopping, or vacuuming
 - Riding a bike
 - Hiking
 - Volleyball

- Basketball
- Golfing (14).
- Regular home blood pressure monitoring is a best practice recommendation for individuals who have been diagnosed with high blood pressure to help their PCP know the treatment is working to reduce hypertension (3).
 - The American Heart Association recommends the use of an automatic, cuff-style, upper arm monitor that fits comfortably. Upper arm blood pressure monitors offer various cuff sizes (Small, Medium, Large, XL) to ensure accuracy. Some brands provide combo cuffs (M/L, XL) or separate cuffs for different arm circumferences (e.g., 7-21 inches).
 - Tips for obtaining an accurate at-home blood pressure reading:
 - Don't smoke, drink caffeinated beverages, or exercise within 30 minutes before measuring blood pressure.
 - Don't put the cuff over clothes. Remove the clothing on the arm used to measure blood pressure.
 - For most individuals, either arm can be used unless otherwise specified by the PCP.
 - Have the individual sit as still as possible and remain quiet if possible. Talking will affect the blood pressure reading.
 - Sit with the arm supported on a flat surface and make sure it is at heart level. The middle of the cuff should be placed on the upper arm at heart level. The bottom of the cuff should be placed directly above the bend of the elbow on bare skin, not over clothing.
 - Take the readings at the same time each day. The PCP should write orders specific to each individual as to how often the blood pressure should be monitored.
 - Only take blood pressure twice in one arm. Record the results and take the record of reading with the individual to their PCP appointments (3).



HOME BLOOD PRESSURE MEASUREMENT INSTRUCTIONS

Before You Measure

- No smoking, caffeinated beverages, alcohol or exercise 30 minutes prior.
- Use a validated device with the correct cuff size. (Visit [Validate BP](#) to find a device you can trust.)
- Empty your bladder.
- Sit quietly for more than 5 minutes and do not talk.

Proper Positioning

- Sit upright with back supported, feet on floor and legs uncrossed.
- Rest your arm comfortably on a flat surface at heart level.
- Wrap the cuff on your bare skin above the bend of the elbow, not over clothing.



During Measurement

- Stay relaxed and do not talk.
- Take at least two readings, 1 minute apart.
- Record all results once measurement is completed and share them with your health care professional to help confirm your office blood pressure category.



American Heart Association recommended office blood pressure categories

BLOOD PRESSURE CATEGORY	SYSTOLIC mm Hg (top/upper number)		DIASTOLIC mm Hg (bottom/lower number)
NORMAL	LESS THAN 120	and	LESS THAN 80
ELEVATED	120-129	and	LESS THAN 80
STAGE 1 HYPERTENSION (High Blood Pressure)	130-139	or	80-89
STAGE 2 HYPERTENSION (High Blood Pressure)	140 OR HIGHER	or	90 OR HIGHER
SEVERE HYPERTENSION (If you don't have symptoms*, call your health care professional.)	HIGHER THAN 180	and/or	HIGHER THAN 120
HYPERTENSIVE EMERGENCY (If you have any of these symptoms*, call 911.)	HIGHER THAN 180	and/or	HIGHER THAN 120

*symptoms: chest pain, shortness of breath, back pain, numbness, weakness, change in vision or difficulty speaking

- * Wait a few minutes and take blood pressure again.
- * If your blood pressure is still high and there are no other signs or symptoms, contact your health care professional.
- * If you are experiencing signs of possible organ damage, such as chest pain, shortness of breath, back pain, numbness, weakness, change in vision or difficulty speaking, call 911.

Learn more at
heart.org/BP

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Resources

- Virginia Healthy Hearts Initiative <https://www.vdh.virginia.gov/heart-disease/virginia-healthy-hearts-initiative/>
- American Heart Association <https://www.heart.org/>

- WHO Guidelines on Physical Activity and Sedentary Behaviors: https://www.ncbi.nlm.nih.gov/books/NBK566045/pdf/Bookshelf_NBK566045.pdf
- Healthy People/Healthy Communities Resources - Eunice Kennedy Shriver Center - <https://shriver.umassmed.edu/programs/healthy-people-healthy-communities/health-promotion-resources/>
- Adult Congenital Heart Association (ACHA) Patient Resource Directory <https://www.achaheart.org/your-heart/resources/patient-resource-directory/>
- The DBHDS Office of Integrated Health Supports Network: <https://dbhds.virginia.gov/office-of-integrated-health/>
- The DBHDS Office of Licensing: <https://dbhds.virginia.gov/clinical-and-quality-management/office-of-licensing/>
- The DBHDS Office of Human Rights: <https://dbhds.virginia.gov/clinical-and-quality-management/human-rights/>

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