Living with
CARDIAC AMYLOIDOSIS

Patient Booklet

Version
October 2025

PANN
Prairie Amyloidosis Nursing Network

CAS
Canadian Amyloidosis Society

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Canadian Amyloidosis Nursing Network

Cardiac amyloidosis is a rare and often debilitating disease. Too often, patients suffer as much if not more prior to their diagnosis being made as they do after. A combination of lack of awareness and signs and symptoms that mimic other more common disorders contributes to a lengthy delay in many patients, as the disease progresses without proper treatment. As a result, patients can often suffer for long periods of time unnecessarily.

However, with new research advancements and dedicated healthcare professionals, the future for amyloidosis patients is improving all the time. We now have new diagnostic techniques to make it faster and easier to detect amyloidosis, and there are many new treatments that are available or in various stages of development. Perhaps most importantly, we have a growing army of healthcare professionals who are dedicated to providing the best care possible. These healthcare professionals are not only dedicated to their own patients, but also to improving awareness and knowledge among others so that care for patients everywhere improves. The authors of this handbook are two examples of this. Their dedication and commitment to improving the lives of patients is remarkable, and they make an important impact doing this every day. Hopefully, this handbook will further their mission, and provide patients and caregivers with a powerful tool to better understand their disease. Knowledge is power, and with tools like this handbook, we continue to take power away from amyloidosis and give it back to our patients.

Dr. Nowell Fine,
Cardiologist and Medical Director of the Cardiac Amyloidosis Clinic in Calgary, AB,
Director of the Canadian Amyloidosis Society

Acknowledgements

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Thank you all for helping to shape this final version.

Living with Cardiac Amyloidosis is a helpful guide for people who have this condition, their families, and anyone who wants to learn more about it. It explains what cardiac amyloidosis is, how it is diagnosed, and how it can be treated.

You don’t need to read the whole guide at once. Rather than reading the booklet from start to finish, we suggest you refer to specific sections or chapters as you are ready. It’s here to help you find answers when you need them. You can use it along with the help and advice from your healthcare team.

Please remember – this guide is for learning only. It does not take the place of medical care from your doctor.

Amyloidosis (pronounced ‘am-uh-loy-DOH-sis’) is a rare condition where abnormal proteins bunch together and deposit in certain organs in your body.

There are many kinds of proteins in the human body. Each one has a special job that helps keep the body healthy. To work properly, proteins need to fold into the right shape. After they finish their job, the body usually breaks them down and reuses them.

In amyloidosis, some proteins fold the wrong way (misfolding). This makes them stop working and hard for the body to break down. These proteins build up, and form clumps called amyloid fibrils. When these fibrils deposit (collect) in organs, they can stop the organs from functioning properly. This damage causes symptoms that get worse over time. The symptoms depend on how much protein has built up and which organs are affected. Certain types of amyloidosis will affect some organs more than others.

The number and location of amyloid deposits can be different from person to person. This means that people with amyloidosis may have different symptoms, even though they have the same disease. Because of this, amyloidosis can be hard to diagnose. It may take time, and patients might see many different doctors or specialists before getting the right diagnosis and treatment.

There are several different types of amyloidosis, depending on the specific protein involved.

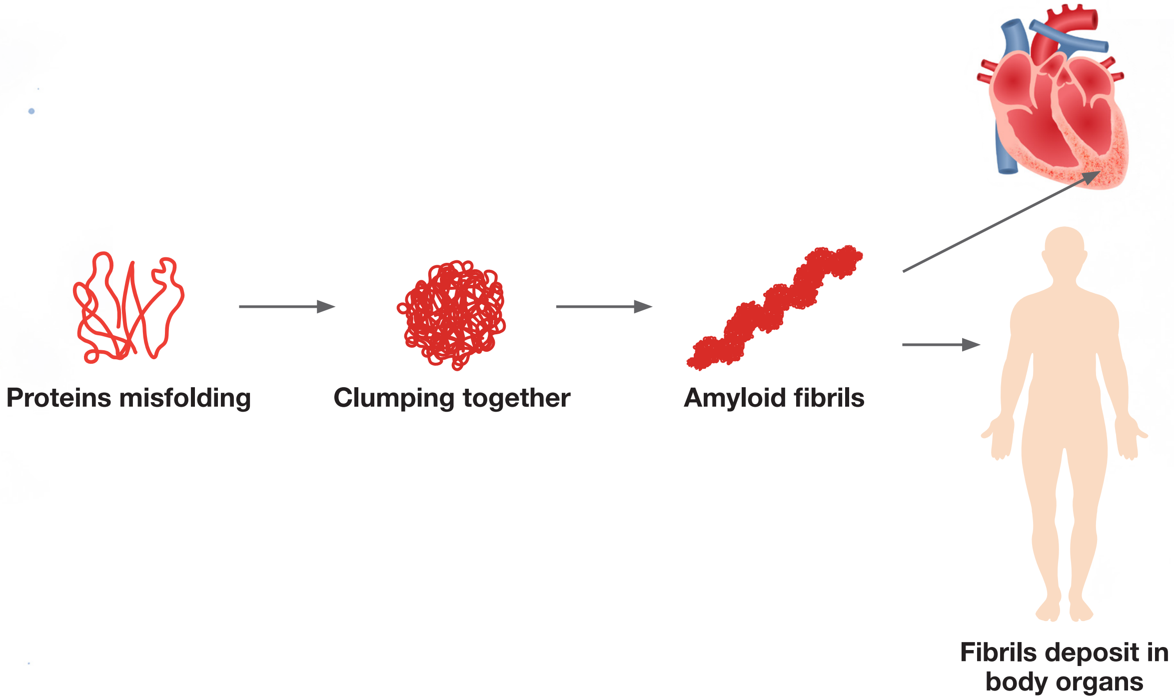
The two most common types of amyloidosis are:

1) Light chain amyloidosis (‘AL’ amyloidosis)

- Caused by a misfolding of ‘light chain’ proteins produced in the bone marrow
- This is considered to be a form of blood cancer

2) Transthyretin (pronounced ‘trans-thy-REH-tin’) amyloidosis (‘ATTR’ amyloidosis)

- Caused by a misfolding of a liver protein named ‘transthyretin’ (also known as ‘prealbumin’).

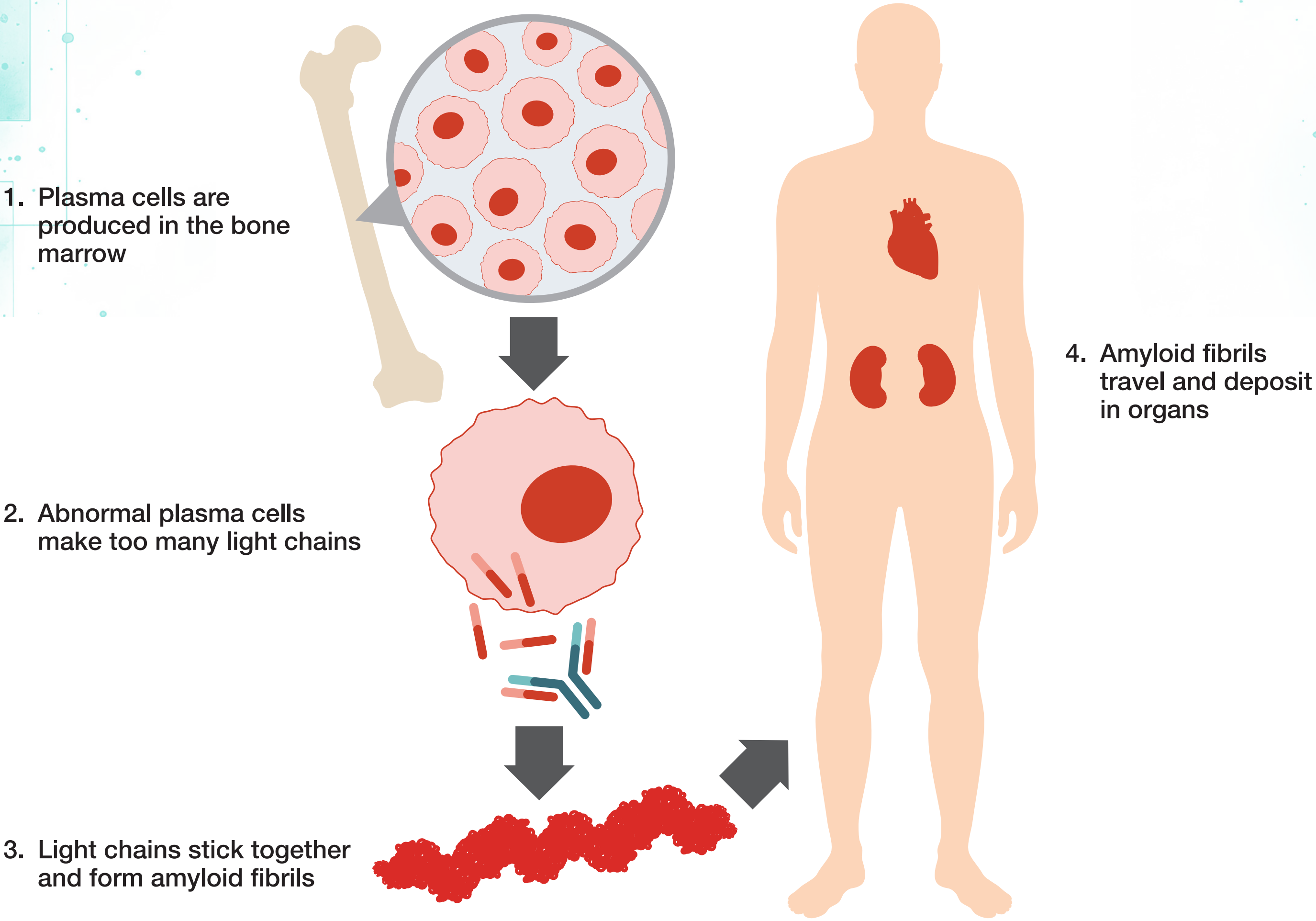


AL amyloidosis is a rare disease that happens when your body makes abnormal proteins called light chains.

Normally, light chains are part of antibodies, which help fight infections. But in AL amyloidosis, the body makes too many light chains that are shaped the wrong way (misfolding). These misfolded proteins stick together, and form clumps called amyloid fibrils.

These amyloid fibrils build up in different parts of the body, like the heart, kidneys, liver, or nerves. Over time, they make it hard for those organs to work properly.

AL AMYLOIDOSIS



1. Plasma Cells are produced in the Bone Marrow

- Bone marrow (the soft tissue inside bones) makes plasma cells, a type of white blood cell.
- Plasma cells make antibodies to help fight infections.

2. Abnormal Plasma Cells Make Too Many Light Chains

- Sometimes, plasma cells don't work properly and start making too many pieces of protein called light chains.
- These light chains are supposed to help your body, but now there are too many.

3. Light Chains Stick Together and Form Amyloid Fibrils

- The extra light chains start to stick together and form long, harmful strands called amyloid fibrils.
- Think of them like tiny pieces of string made from broken parts.

4. Amyloid Fibrils Travel and Deposit in Organs

- These harmful fibrils move through the blood and get stuck in important organs like the heart, kidneys, or liver.
- This causes those organs to stop working properly, which can make someone very sick.

WHAT ARE THE SYMPTOMS OF AL AMYLOIDOSIS?

Symptoms of AL amyloidosis can be hard to recognize because they are similar to other more common diseases. The symptoms experienced depend on the number of amyloid deposits and which organs are affected. Over time, symptoms can get worse.

Cardiac (Heart) Symptoms

When amyloid deposits build up in the heart, it becomes stiff and thick, making it harder to pump blood to the rest of the body.

Common cardiac symptoms include:

- Swollen legs, feet and belly, rapid weight gain (due to fluid buildup)*
- Shortness of breath
- Irregular heart rhythm (arrhythmia)
- Low blood pressure
- Feeling unusually tired/fatigued

**Your healthcare team may refer to these symptoms as 'heart failure'.*

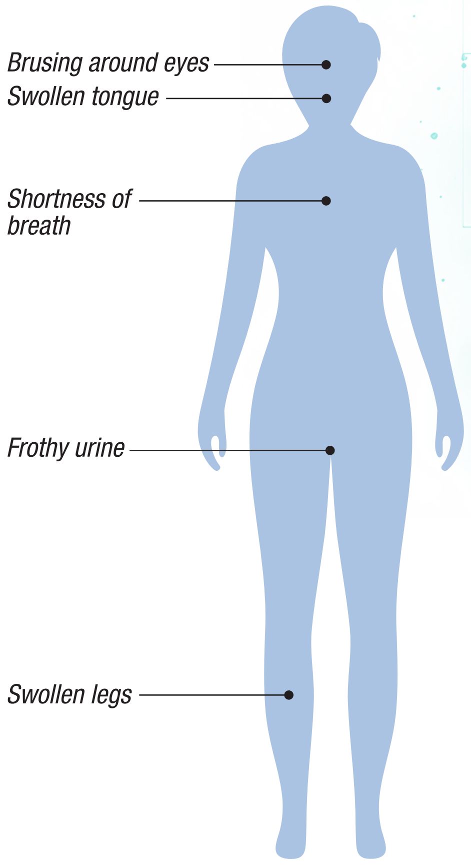
Renal (Kidney) Symptoms

When amyloid deposits build up in the kidneys, they can become damaged, affecting their ability to filter and clean the blood. This makes it harder for the kidneys to keep the right balance of salt and water in the body causing a buildup of fluid.

Common renal symptoms include:

- Swollen legs, feet, and belly, rapid weight gain (due to fluid buildup)
- Frothy (bubbly) urine
- Anemia or low hemoglobin (a component of red blood cells)
- Decrease or loss of appetite
- Feeling unusually tired/fatigued

MOST FREQUENT SYMPTOMS



Other common symptoms include:

- Dizziness or light headedness
- Bruising (e.g., around the eyes, known as raccoon eyes)
- Skin rash, nail changes
- Swollen tongue (macroglossia)
- Swelling of joints
- Peripheral neuropathy: pain, numbness, and tingling in the extremities (hands and/or feet)
- Digestive problems: diarrhea, constipation, bloating, nausea/vomiting, poor appetite, weight loss

Talk to your healthcare professional about symptoms you may be experiencing.

HOW IS AL AMYLOIDOSIS DIAGNOSED?

Your healthcare team will use several tests to diagnose AL amyloidosis including:

Blood Tests and Urine Tests

- **Serum free light chain assay:** measures the level of light chain proteins in your blood
- **Complete Blood Count (CBC):** measures red blood cells, white blood cells, and platelets
- **Cardiac (heart) biomarkers (e.g., BNP, NT-proBNP, troponin):** measure how much the heart is affected by amyloidosis
- **Kidney function tests (e.g., creatinine clearance, eGFR)**
- **Liver function tests**
- **24-hour urine test:** measures protein in urine to check kidney health
- **Serum Protein Electrophoresis:** measures the types of proteins in your blood to ensure they are in the right balance

Tissue Biopsy

- **Bone Marrow Biopsy:** can identify abnormal blood cells in the bone marrow (such as abnormal plasma cells)
- Other types of tissue biopsy: examines tissue from affected organs to look for amyloid fibrils (e.g., heart, kidney, etc)

COMMON CARDIAC TESTS

Electrocardiogram (ECG)

- An ECG is a recording of the electrical signals from your heart
- It can reveal conditions like irregular heartbeat (i.e., arrhythmias), among other findings, which may be related to amyloidosis

Echocardiogram (ECHO)

- An ECHO is an ultrasound of the heart
- It uses sound waves to take moving pictures of your heart
- It assesses the speed and direction of blood flow through the heart and provides other details about the function of your heart
- Specific changes can occur to heart muscle because of amyloidosis (such as it becomes thicker) which can be identified on the ECHO and help provide additional information for your healthcare team

Cardiac Magnetic Resonance Imaging (Cardiac MRI)

- A cardiac MRI uses radio waves and magnets to create images of your heart to look for abnormalities

Other specialized tests may be needed to confirm the diagnosis. These will be discussed in further detail with you. Some tests may be completed before your doctor’s visit, while others may be performed after.

HOW IS AL AMYLOIDOSIS TREATED?

Treatment focuses on the bone marrow, where plasma cells make abnormal light chain proteins. Hematologists (doctors that specialize in blood disorders) and/or oncologists (doctors that specialize in cancer) prescribe these treatments to manage the condition.

AL amyloidosis is usually treated with:

- **Chemotherapy:** Prescribed by a hematologist or oncologist to reduce amyloid protein production
- **Stem cell transplantation** (in some cases only)

Supportive Care

Your healthcare team will help manage symptoms and complications of the disease. This can include medications, lifestyle changes, and therapies like physical therapy or nutritional support.

For more information on supportive care, please refer to page 24.

Clinical Trials

Learning about clinical trials can be an important part of your care. In a rare disease such as amyloidosis, treatment options can be limited, and clinical trials (where drugs are carefully studied in real people) may be a way to access other new types of therapies. To learn more about clinical trials talk to your healthcare team and/or local amyloidosis expert.

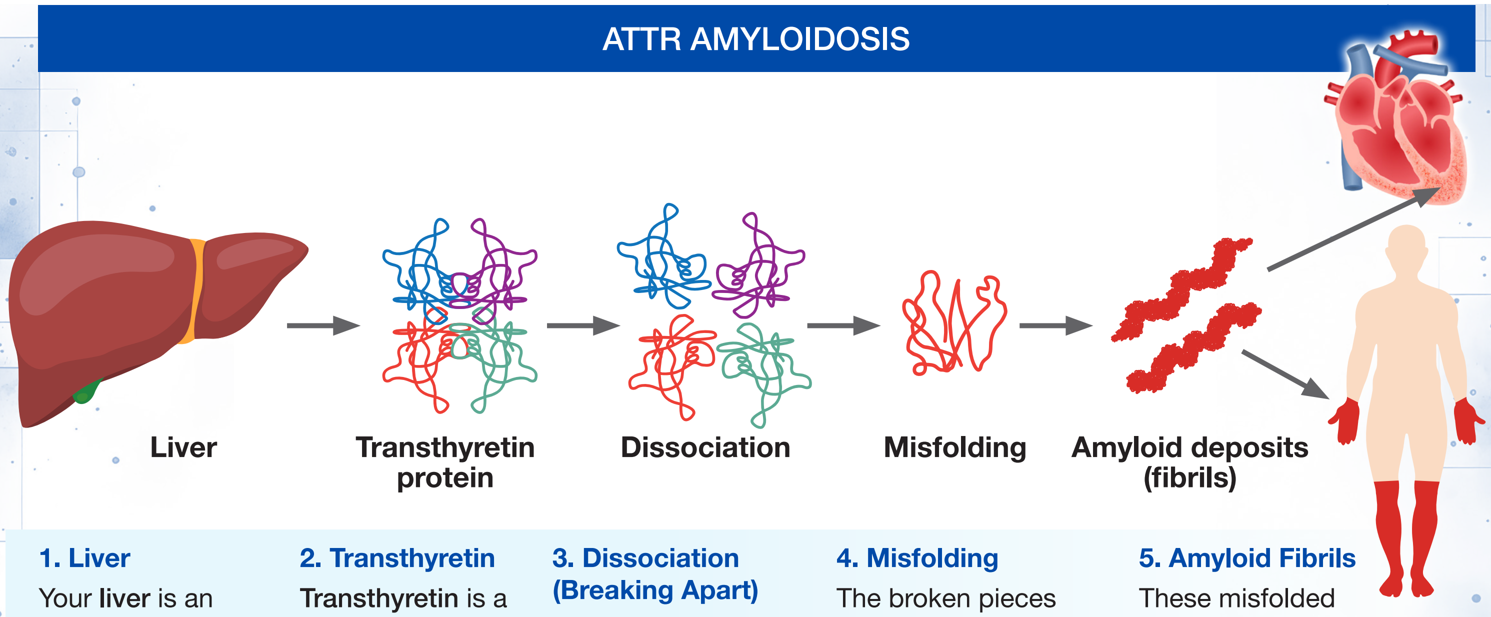
Transthyretin (TTR) is a protein made by the liver. Its role is to transport the hormone thyroxine as well as retinol (vitamin A) around the body, hence its name transthyretin **(pronounced 'trans-thy-REH-tin')**.

In transthyretin amyloidosis (ATTR), transthyretin folds the wrong way (misfolds). These misfolded proteins clump together and form amyloid deposits (also called fibrils). The amyloid deposits build up in different organs.

ATTR most often affects the heart and the peripheral nervous system.

- The peripheral nervous system is the network of nerves that sends messages between your brain, spinal cord, and the rest of your body. It helps you feel, move, and sense what's happening around you.
- When the heart is affected, the condition is called cardiac amyloidosis, or "ATTR-CM." "CM" stands for cardiomyopathy, which means the heart muscle becomes thick, stiff, or weak. This makes it harder for the heart to pump blood properly to the rest of the body.

ATTR AMYLOIDOSIS



1. Liver

Your **liver** is an organ that helps clean your blood and makes important proteins.

One of these proteins is called **transthyretin**.

2. Transthyretin

Transthyretin is a protein that helps carry vitamins and hormones in your blood.

3. Dissociation (Breaking Apart)

Sometimes, transthyretin **breaks into smaller pieces**. This is called **dissociation**.

Think of it like a puzzle falling apart.

4. Misfolding

The broken pieces of the protein start to **fold the wrong way**.

When proteins are folded the wrong way, they don't work properly and can become sticky.

5. Amyloid Fibrils

These misfolded proteins **stick together and form long strands** called **amyloid fibrils**.

These fibrils can build up in the body and **damage important organs** like the heart or nerves.

Types of ATTR Amyloidosis

ATTR can be further divided into two main types: wild-type and hereditary (genetic).

Wild-type ATTR amyloidosis (ATTRwt)

- Develops for unknown reasons as people get older and is NOT inherited. This means you will not get it from your family.
- Is far more common than hereditary amyloidosis (hATTR)

Hereditary ATTR amyloidosis (hATTR)

- Is caused by an abnormal gene that is inherited. This means it was passed down from one of your parents.
- Is far less common than the wild-type ATTR

Wild-Type Amyloidosis (ATTRwt)

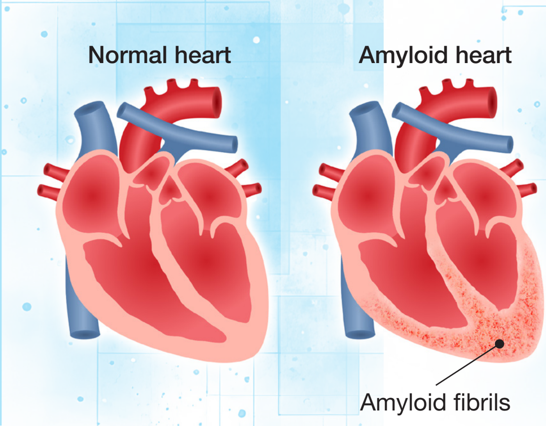
In ATTRwt amyloidosis, the transthyretin (TTR) protein becomes unstable with age, making it prone to misfolding. The onset of this condition is gradual and it progresses slowly over time. ATTRwt affects older people, most often men over 65 years of age.

WHAT ARE THE SYMPTOMS OF WILD-TYPE ATTR AMYLOIDOSIS?

Symptoms of ATTRwt amyloidosis can be hard to recognize because they are similar to other more common diseases. The symptoms experienced depend on the amount of amyloid deposits and which organs are affected. Over time symptoms can get worse.

Cardiac (Heart) Symptoms

When amyloid deposits build up in the heart, it becomes stiff and thick, making it harder to pump blood to the rest of the body.



Common cardiac symptoms include:

- Swollen legs, feet and belly, leading to rapid weight gain (due to fluid buildup)*
- Shortness of breath
- Irregular heartbeats (arrhythmia) or palpitations
- Low blood pressure
- Feeling unusually tired/fatigued

**Your healthcare team may refer to these symptoms as "heart failure".*

Other common symptoms include:

- Weakness, numbness, or burning pain of nerves in hands and/or feet (polyneuropathy)
- Carpal tunnel syndrome (affecting one or both wrists)**
- Spinal stenosis (often in the lower back causing back or leg pain or numbness)**
- Tendon problems or rupture (e.g., biceps tendon rupture, shoulder rotator cuff tear)
- Dizziness or lightheadedness
- Stomach problems
    - Diarrhea, constipation (or alternating between both)
    - Nausea/vomiting
    - Bloating—feeling of fullness even when small amounts are eaten
    - Poor appetite, weight loss
- Urinary incontinence
- Erectile dysfunction
- Kidney problems, which can lead to swelling of legs, arms and belly

***Carpal tunnel syndrome and spinal stenosis often happen before the onset of cardiac symptoms, sometimes even years before, but can recur as the disease progresses.*

Talk to your healthcare professional about symptoms you may be experiencing.

HOW IS WILD-TYPE ATTR AMYLOIDOSIS DIAGNOSED?

Your doctor will gather information from different sources. They will ask about your symptoms, do a physical exam and ask you to complete some medical tests. Your healthcare team will work together to assess which type of amyloidosis you might have. This is an important step because different types of amyloidosis are managed in different ways.

Testing for ATTRwt includes screening for AL (light chain) amyloidosis as well as hereditary amyloidosis (hATTR).

Your healthcare team will use several tests to diagnose ATTRwt amyloidosis, including:

Blood Tests and Urine Tests

- **Serum free light chain assay:** measures the level of light chain proteins in your blood
- **Complete Blood Count (CBC):** measures red blood cells, white blood cells, and platelets
- **Cardiac (heart) biomarkers (e.g., BNP, NT-proBNP, troponin):** measure how much the heart is affected by amyloidosis
- **Kidney function tests (e.g., creatinine clearance, eGFR)**
- **24-hour urine test:** measures protein in urine to check kidney health

COMMON CARDIAC TESTS

Electrocardiogram (ECG)

- An ECG is a recording of the electrical signals from your heart
- It can reveal conditions like irregular heartbeat (i.e., arrhythmias), among other findings, which may be related to amyloidosis

Echocardiogram (ECHO)

- An ECHO is an ultrasound of the heart
- It uses sound waves to take moving pictures of your heart
- It assesses the speed and direction of blood flow through the heart and provides other details about the function of your heart
- Specific changes can occur to heart muscle because of amyloidosis (such as it becomes thicker), which can be identified on the ECHO and help provide additional information for your healthcare team

Cardiac Magnetic Resonance Imaging (Cardiac MRI)

- A cardiac MRI uses radio waves and magnets to create images of your heart to look for abnormalities

COMMON CARDIAC TESTS (cont'd)

PYP Scan or Pyrophosphate Scan (Nuclear Scintigraphy)

- A PYP Scan is a heart imaging test
- A small amount of dye is injected into your bloodstream through an intravenous line
- After 1–3 hours, a special camera takes pictures of your heart
- These pictures can help your healthcare team understand if amyloid deposits are present in your heart

Tissue Biopsy

- Examines tissue biopsied from affected organs (such as the heart) to look for amyloid deposits
- A tissue biopsy is not often needed but may be necessary in certain situations

OTHER COMMON TESTS

Genetic Testing

- Will help confirm or rule out the hereditary form of amyloidosis (hATTR)
- Determines whether other family members may be at risk because the abnormal gene that causes hATTR can be passed down to biological children
- Is usually performed using blood or saliva samples
- May be required for certain provincial drug plans to cover medications used to treat amyloidosis
- If genetic testing is suggestive of hATTR, genetic counselling is recommended to help you and your family members understand the test results and potential steps to take

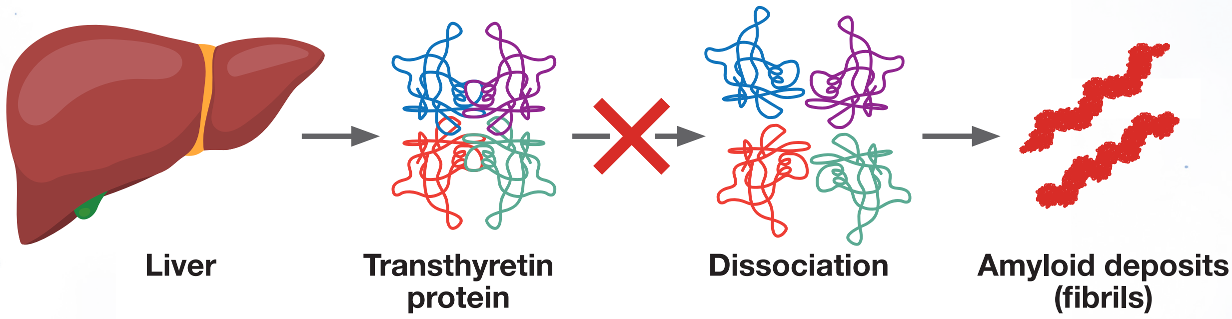
Other specialized tests may be needed to confirm the diagnosis. These will be discussed in further detail with you. Some tests may be completed before your doctor's visit, while others may be performed after.

HOW IS WILD-TYPE ATTR AMYLOIDOSIS TREATED?

In wild-type ATTR amyloidosis, specific medications aim to keep protein from changing into the abnormal form. While no current therapies can reverse damage caused by amyloid protein deposits, some drugs can prevent or slow the progression of the disease.

MEDICATIONS USED TO TREAT WILD-TYPE AMYLOIDOSIS

Medications used to treat wild-type amyloidosis are called **STABILIZERS**. These drugs stabilize the transthyretin protein and stop it from forming amyloid deposits. This prevents further build up in the heart or other organs.



Supportive Care

Your healthcare team will help manage symptoms and complications of the disease. Supportive care can include medications, lifestyle changes, and therapies like physical therapy or nutritional support.

For more information on supportive care and medications, please refer to page 24.

Your healthcare team will work with you to develop an individual treatment plan.

Clinical Trials

Learning about clinical trials can be an important part of your care. In a rare disease such as amyloidosis, treatment options can be limited, and clinical trials (where drugs are carefully studied in real people) may be a way to access other new types of therapies. To learn more about clinical trials talk to your healthcare team and/or local amyloidosis expert.

While there are currently no medications approved to remove amyloid deposits (“degraders”), this possibility is under investigation.

HEREDITARY TRANSTHYRETIN AMYLOIDOSIS (hATTR)

Hereditary transthyretin amyloidosis (hATTR) is a rare, inherited form of amyloidosis. A genetic variant (abnormality) in the transthyretin (TTR) gene causes a change in the gene's instructions. This causes the transthyretin protein to become unstable, misfold, and form amyloid deposits. These deposits build up in different organs and nerves, affecting function. When your heart is affected, it is called cardiac amyloidosis.

There are more than 120 gene variants known to cause hATTR and these may be passed down from parents to children. Depending on the specific gene variant, symptoms can begin as early as age 30, although most symptoms don't appear until later in life. Early identification and treatment are essential to improve outcomes.

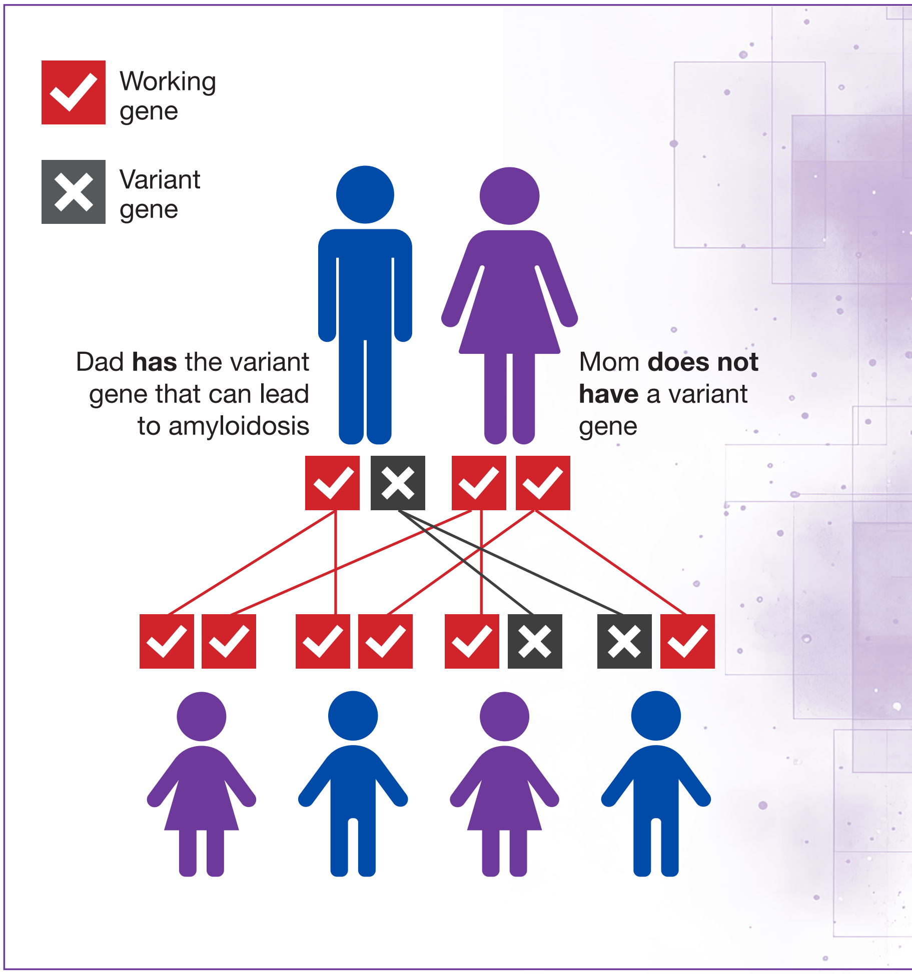
How is hATTR Inherited?

Every child inherits two copies of the TTR gene: one from their mother and one from their father. Hereditary ATTR is inherited in an autosomal dominant pattern. This means that inheriting one copy of the TTR gene with a variant causes an increased risk of developing hATTR amyloidosis.

Individuals with hATTR have inherited the gene from one of their parents. A parent with hATTR has a 50% likelihood of passing on the variant to each of their children. In fact, all close biological relatives (parents, siblings, and children) of someone with hATTR will have a 50% likelihood of having the same TTR variant. Rarely, a new ("de novo") gene variant occurs for the first time in someone with amyloidosis that is not inherited from a parent.

Inheriting a TTR gene variant does not always lead to amyloidosis (disease causing symptoms). Family members with the disease caused by the same gene variant may not necessarily develop the same symptoms, have the same symptom severity, or have symptoms starting at the same age.

Even without symptoms, a parent with a gene variant can still pass this on to a child. For this reason, genetic testing for the variant in family members can help determine whether children are at risk for amyloidosis.



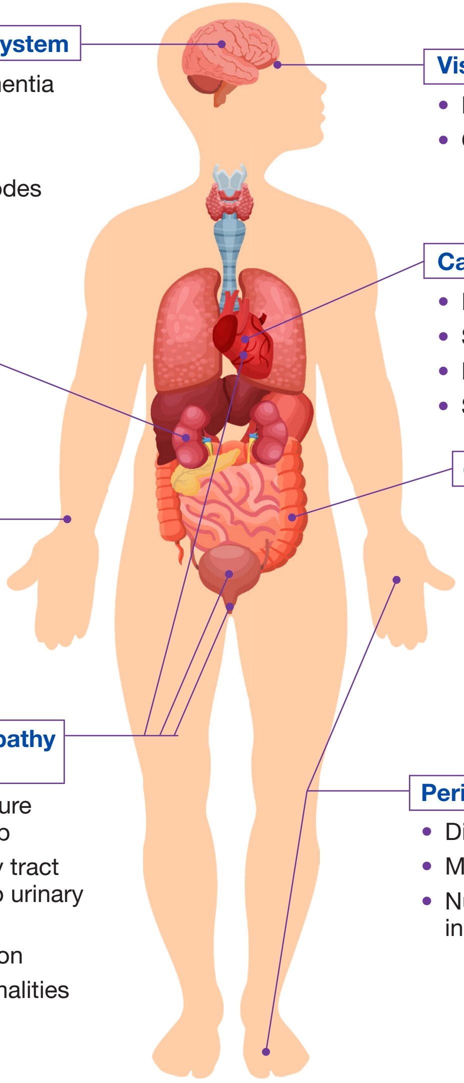
WHAT ARE THE SYMPTOMS OF hATTR?

Initial symptoms of hATTR amyloidosis usually appear between 30 and 70 years of age. hATTR can be difficult to diagnose as symptoms are not always specific, often seem unrelated, and may be confused with other more common conditions.

In hereditary ATTR, the abnormal transthyretin protein most commonly builds up in the peripheral nerves (nerves that control sensation and movement in the extremities, like hands and feet), autonomic nerves (nerves that control organ function, such as digestion and blood pressure), and the heart. Other organs can be involved including the eyes and gastrointestinal tract.

Common symptoms of hereditary ATTR include:

- Tiredness/fatigue
- Problems with digestion, bowel or bladder function
- Blurred vision
- Shortness of breath
- Swelling (edema) in the legs and feet
- Irregular heartbeat
- Hand pain, numbness, or tingling in your fingers
- Pain or numbness in your lower back or legs
- Lumbar spinal stenosis (in the lower part of the spine)
- Bicep tendon rupture
- Unexplained weight loss
- Lightheadedness when you stand up
- Non-heart-related symptoms, such as carpal tunnel syndrome and joint, spine, or nerve problems can develop before heart problems in people with hATTR



Central nervous system

- Progressive dementia
- Headache
- Seizures
- Stroke-like episodes

Kidneys

- Protein in urine
- Renal failure

Carpal tunnel syndrome

Autonomic neuropathy (nerve damage)

- Low blood pressure when standing up
- Recurrent urinary tract infections (due to urinary retention)
- Sexual dysfunction
- Sweating abnormalities

Visual

- Blurred vision
- Glaucoma

Cardiovascular

- Irregular heart rhythm
- Swelling in legs or feet
- Dizziness when standing up
- Shortness of breath

GI manifestations

- Nausea and vomiting
- Feeling full without eating much
- Diarrhea
- Severe constipation
- Alternating episodes of diarrhea and constipation
- Unintentional weight loss

Peripheral Nervous System

- Difficulty walking
- Muscle weakness
- Numbmess/burning/tingling in hands/feet

Talk to your healthcare professional about symptoms you may be experiencing.

HOW IS hATTR AMYLOIDOSIS DIAGNOSED?

hATTR amyloidosis can affect many organs and cause a variety of symptoms, making it challenging to diagnose. However, there are several tests that can help determine if you have hATTR amyloidosis. Some of these common diagnostic tests include:

Blood Tests

- **Cardiac (heart) biomarkers (e.g., BNP, NT-proBNP, troponin):** measure how much the heart is affected by amyloidosis
- **Kidney function tests (e.g., creatinine clearance, eGFR)**
- **Liver function tests**

COMMON CARDIAC TESTS

Electrocardiogram (ECG)

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Tissue Biopsy

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- A tissue biopsy is not often needed but may be necessary in certain situations

OTHER COMMON TESTS

Genetic Testing

- Will confirm or rule out the hereditary form of amyloidosis (hATTR)
- Is usually performed using blood or saliva samples
- Determines if family members may be at risk because the gene problem that causes hATTR can be passed down to biological children
- May be required for some provincial drug plans to cover medications used to treat amyloidosis

ADVICE FROM A GENETIC COUNSELLOR:

"hATTR is a genetic condition that can run in families. Talking to your family about your diagnosis can help them access the care they need."

Tara, Edmonton, Alberta

GENETIC TESTING - WHY IS IT IMPORTANT?

If you are diagnosed with ATTR amyloidosis, genetic testing is recommended to find out whether you have the wild-type (ATTRwt) or hereditary type (hATTR). Genetic testing means checking to see if the type of amyloidosis you have is caused by a gene variant (abnormality) and is something that family members can inherit. This allows healthcare providers to consider the most appropriate treatments for you and your family. Treatments for hATTR may be most effective when administered early, before abnormal amyloid proteins build up.

If genetic testing confirms you have hATTR, genetic counselling will be recommended. This is to help you and your family members understand the test results and the next steps to take.

GENETIC COUNSELLING

Genetic counselling gives information about how genetic conditions, such as hATTR, may affect you or your family. Counselling is important after genetic testing because specialized genetic counsellors can explain test results and potential health consequences for you and your family members, including children.

A genetic counselling appointment typically involves discussing genetic testing results, taking a family history, and identifying whether other family members may be at risk for amyloidosis. Genetic counsellors can advise and support patients on ways to communicate the news of genetic variants to other family members. Although privacy laws restrict the ability of healthcare professionals to share information directly to other potentially affected relatives, they can provide written letters that explain the genetic findings, which you can give to family members.

It may be surprising for your relatives to learn that they may also be at risk for amyloidosis. A genetic counsellor can help families explore the medical and emotional aspects of genetic hATTR testing.

WHO ELSE SHOULD GET TESTED?

Once a genetic variant is identified within a family, all first-degree relatives (parents, siblings, and children) are eligible for genetic counselling. In general, genetic testing is offered to relatives to assess for the specific variant that was discovered within that family. This is called “predictive genetic testing” and is available to other family members even before symptoms develop.

WHAT IF MY FAMILY MEMBERS DO NOT WANT GENETIC TESTING?

Genetic counselling is available to family members to allow them to learn more about amyloidosis, and the potential benefits and drawbacks of testing. Family members should not feel obligated to complete genetic testing. Genetic testing is optional. There are many things to consider before having a genetic test. Should a family member choose not to have genetic testing, suggestions for how to watch for the development of symptoms of hATTR in that person may be recommended. It is important to know that without genetic testing, treatment for amyloidosis may be delayed.

TIPS FOR TALKING WITH YOUR FAMILY ABOUT GENETIC TESTING FOR hATTR AMYLOIDOSIS

It can be hard to talk with loved ones about genetic testing for hATTR amyloidosis. For some, genetic results come as a relief, removing some of the uncertainty surrounding their risk for the disease. For others, learning that they or someone in their family has hATTR amyloidosis can be scary. Some may feel guilty, angry, anxious, or depressed. If you are feeling this way, visit the "Resources" section on page 63 for additional sources of help.

It is important to remember that all humans have unique genetic make-ups that are passed on to children—we do not choose what we pass along genetically to our children.

Potential benefits of talking with your family about genetic testing include:

- Helping family members understand their risk for hATTR amyloidosis
- Helping family members watch out for signs of hATTR amyloidosis and start screening earlier
- Family members may find it empowering to use this knowledge to take control of their health

Potential risks to keep in mind when talking to your family about genetic testing:

- Learning that you or someone in your family has, or is at risk for a disease can be scary
- Family members may find it upsetting to get genetic testing if other family members have passed away due to hATTR amyloidosis
- Knowledge about passing a TTR gene variant on to one's children can lead to many emotions, such as guilt or anger

---

PREPARING TO DISCUSS hATTR WITH FAMILY MEMBERS

Arm yourself with facts:

The more you know about hATTR amyloidosis, the more you can help answer questions for your family members. You will also be more prepared to manage your condition. Use the information in this booklet to familiarise yourself with the aspects of the condition.

Consider this:

A family member may inherit the TTR gene variant, but that does not mean they will develop hATTR amyloidosis. You may want to include this fact in your discussion. This may also be something your family member can discuss further with a healthcare professional.

Anticipate questions:

It may be helpful to write down the questions you asked when you were first diagnosed with hATTR amyloidosis. This may give your family members some ideas of questions to ask their own healthcare professionals. Each person may have a different reaction to your story. It is important to take each point of view into consideration.

Plan ahead:

Create an outline of the topics you'd like to include and the points you'd like to make during your conversations.

HOW TO START A CONVERSATION WITH YOUR FAMILY MEMBERS

Share the story or your journey:

If you feel comfortable, include points from your personal experience with hATTR amyloidosis. This may help to have a productive and informed conversation.

Start with the basics:

Beginning the conversation could be as simple as "I want to talk to you about a condition I have." You can help set the tone of the discussion by sharing the information that seems most important to the relative you are speaking with. Consider talking about your symptoms, the healthcare professionals you visited, your journey to diagnosis (including any misdiagnosis you may have received), and how you manage the condition.

Explain that hATTR amyloidosis is hereditary:

Highlighting the hereditary nature of the condition can help your family members understand why your condition may directly affect them. Talk to your healthcare professional. There may be tools available to help map your family health history to see who may appear to be at risk for the condition.

Describe the variability in symptoms:

Help your family members understand that hATTR amyloidosis can affect several systems in your body, including the nervous system (nerves), cardiac (heart), and gastrointestinal (digestive) tract. Remember that symptoms may vary widely from patient to patient, even among individuals in the same family. Importantly, while symptoms may vary, some families do see a pattern develop. The age that symptoms first appear may vary, ranging from the mid-20s to the mid-60s or older. These facts may help your family members stay open-minded about recognizing symptoms in their own history or in the future.

Educate on the possibility of misdiagnosis:

Explain that misdiagnosis is common with hATTR amyloidosis because the symptoms resemble those of other conditions. Knowing these signs can help family members recognize symptoms sooner and work with a healthcare professional to receive an accurate diagnosis.

HOW TO START A CONVERSATION WITH YOUR FAMILY MEMBERS (cont'd)

Discuss diagnosis:

Encourage family members to tell their healthcare professional that a diagnosis of hATTR amyloidosis has been made in a family member and to discuss next steps. Your family member's healthcare provider may order some basic tests or refer them to a specialist.

Talking with children:

Speaking to younger children and teenagers about hATTR amyloidosis can be difficult. You may ask yourself if or when you should have the conversation. Try to have age appropriate conversations. Choose a time that is best for the child/teenager.

Here are some suggestions that may help with the discussion:

"I have some news to share with you. We found out what is going on with your dad."

"What are you thinking right now? It's okay to be scared, angry, or anything else. I feel sad and a little scared myself."

It is important to be open with children and to encourage them to ask questions. Continue to offer support. This will help them feel secure at a time of uncertainty.

Encourage a visit with a healthcare professional:

Even if your family members have not experienced symptoms, it is still important for them to speak with their healthcare professional. Together, they can discuss action plans and next steps.

HOW IS hATTR TREATED?

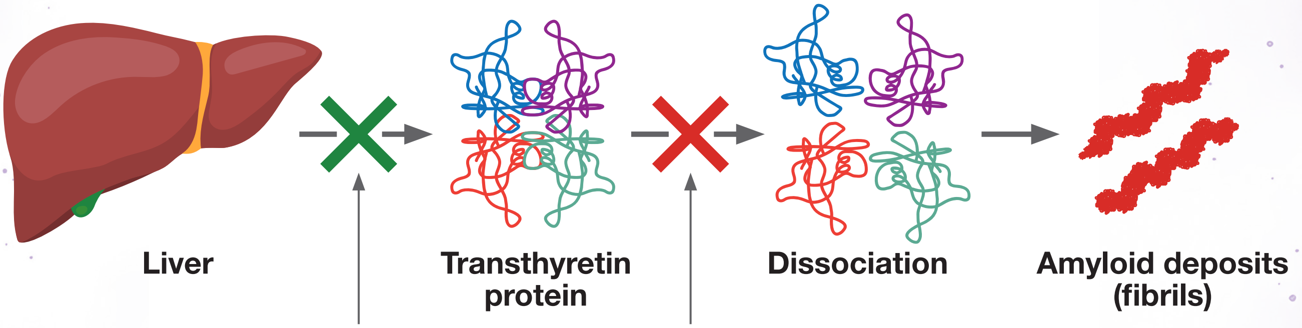
In hATTR amyloidosis, specific medications aim to either reduce the amount of abnormal protein or stop protein from changing into the abnormal form.

While no current therapies can reverse damage caused by amyloid protein deposits, some new drugs can prevent or slow the progression of the disease. Your treatment will depend on which organ(s) in your body are affected and how far the disease has advanced.

Medications used to treat hereditary amyloidosis aim to do one of the following:

1. **SILENCERS: Stop the production of the transthyretin protein** These drugs block the gene that makes the protein so that amyloid deposits don’t build up any further in the heart or other organs.
2. **STABILIZERS: Stabilize the transthyretin protein** These drugs stop the protein from forming amyloid deposits to prevent further build up in the heart or other organs.

MEDICATIONS USED TO TREAT HEREDITARY AMYLOIDOSIS (hATTR)



The green X represents how silencer medications work

The red X represents how stabilizer medications work.

Supportive Care

Your healthcare team will help manage symptoms and complications of the disease. Supportive care can include medications, lifestyle changes, and therapies like physical therapy or nutritional support.

For more information on supportive care and medications, please refer to page 24.

Your healthcare team will work with you to develop an individual treatment plan.

Clinical Trials

Learning about clinical trials can be an important part of your care. In a rare disease such as amyloidosis, treatment options can be limited, and clinical trials (where drugs are carefully studied in real people) may be a way to access other new types of therapies. To learn more about clinical trials talk to your healthcare team and/or local amyloidosis expert.

While there are currently no medications approved to remove amyloid deposits (“degraders”), this possibility is under investigation.

SUPPORTIVE TREATMENT FOR CARDIAC AMYLOIDOSIS

Supportive treatments do not cure amyloidosis but are important to help make symptoms less of a problem and improve your quality of life. Things such as age, general health, and severity of amyloidosis are considered when deciding on supportive treatments.

Common symptoms of amyloidosis include swelling, blood pressure problems, heart rate problems, breathing problems and fatigue. Medications can play a crucial role in managing these symptoms.

Some common medications used for other forms of heart conditions may not really help people with amyloidosis or may even make symptoms worse.

Common types of medications used in amyloidosis or other heart conditions

Diuretics (“water” pills):

- Used to keep your weight stable and reduce symptoms by increasing urination and flushing salt and water from the body
- Many people with cardiac amyloidosis will be prescribed a diuretic, but too much diuretic may cause low blood pressure related problems such as dizziness

ß-blockers (beta-blockers) — the names of these medications usually end in “…lol”, for example, metoprolol

- Used alone or in combination to treat high blood pressure, control heart rate and rhythm, and manage other kinds of heart problems
- These agents don’t slow disease progression and usually do not relieve symptoms in patients with cardiac amyloidosis
- In some patients they may worsen fatigue and hypotension (low blood pressure) and should be used cautiously

ACE inhibitors (angiotensin converting enzyme inhibitors) — the names of these medications usually end in “….pril”, for example, ramipril

ARBs (angiotensin receptor blockers) — the names of these medications usually end in “…sartan”, for example, losartan

- Used alone or in combination to treat high blood pressure and manage other kinds of heart problems
- These agents don’t slow disease progression and usually do not relieve symptoms in patients with cardiac amyloidosis
- In some patients they may worsen fatigue and hypotension (low blood pressure) and should be used cautiously

Digoxin:

- Used to slow and strengthen the heartbeat
- In patients with cardiac amyloidosis, digoxin may be less effective and potential harmful when compared to its use in other heart problems. Digoxin is usually avoided in amyloidosis.

Calcium channel blockers:

- Used to control heart rate and blood pressure
- There are several types of the calcium channels blockers—these medications may be less effective for patients with cardiac amyloidosis and may make a patient feel worse
- These drugs have a variety of names—your pharmacist is a good resource person if you are unsure of if you are taking a calcium channel blocker
- These drugs have nothing to do with calcium that you get from dairy products or calcium tablets

Amiodarone:

- Used to control heart rhythm and improve symptoms
- Often used in cardiac amyloidosis to treat heart rhythm problems, but it can interact with other medications and cause side effects
- Your healthcare team will monitor you carefully if you are prescribed this medication

> ***ADVICE FROM A PHARMACIST:***
>
> ***"It is really important to take all of your medications exactly as directed by your doctor or nurse practitioner. Never stop taking a medication on your own without talking to your doctor or pharmacist. Make sure you call your pharmacist with any questions you have about any of your medications."***
>
> *Josh, Heart Function Clinic Pharmacist, Regina*

GENERAL RULES FOR MEDICATIONS

- NEVER STOP TAKING a medication that is used to control blood pressure or help with heart problems on your own "cold-turkey" (unless this is part of a 'Sick Day Plan' that a healthcare professional has helped you develop). Always talk to your healthcare team and/or pharmacist before stopping one of these medications to get proper instructions on how to safely go off a medication.
- Store medications at room temperature and out of direct sunlight on a closed container.
- If you need to go to the hospital or emergency room, take all of your medications with you. Hospitals have supplies of common medications, but they do not stock specialized medications like those used only in the treatment of cardiac amyloidosis.
- It is a good idea to get a Medical Alert bracelet or necklace that lists your medications and/or medical problems.
- Reach out to your pharmacist with any questions you may have about your medications.
- It is important to be aware of both benefits and risks of any medication you take. Reach out to your pharmacist with any questions you may have about your medications.
- Watch the number of refills remaining on your prescription labels. Ensure you plan ahead to get renewals by contacting the prescriber for an appointment or to request more refills. In some cases, a pharmacist may be able to extend your refills for a short period of time.

Medical Devices:

- Patients with cardiac amyloidosis may be at higher risk of abnormal heart rates and other "electrical" system problems in the heart
- Some people have pacemakers (devices that regulate heartbeat) or defibrillators (ICDs, devices that shock the heart out of an irregular heartbeat) implanted

LEARNING TO LIVE WITH AMYLOIDOSIS

Empower yourself! You can make positive changes in your life to promote wellbeing. This section offers practical advice for daily living.

TAKE CARE OF YOUR EMOTIONAL HEALTH

Many people find it difficult when they are diagnosed with a rare disease like amyloidosis. If you are feeling stressed, depressed, or unusually worried, don't hide these feelings. Talk to your healthcare provider. Visit the "Resources" section on page 63 of this booklet for some suggested resources.

TAKE CARE OF YOUR PHYSICAL HEALTH

- If you notice changes in any area of your health let your health provider know.
- Keep all scheduled medical appointments even if you are feeling well.
- Getting sick can be very serious when you have a heart condition.
    - Speak to your healthcare provider to see if it is recommended that you get a flu shot yearly. The area you live in may offer flu clinics.
    - Speak to your healthcare provider to see if it recommended you get the pneumonia shot Talk to your healthcare provider about this as you may need a prescription for the vaccine.
    - Speak to your healthcare provider about getting the COVID vaccine.

CONSERVE YOUR ENERGY

- Set aside time each day to rest; consider an hour a day.
- Aim for balance.
    - Balance activity with rest periods.
    - Balance hard activities with easy activities.
    - Do activities when you feel your best. Tiredness and energy levels can change quickly and be hard to predict.
- Plan ahead.
    - Plan your chores and daily activities ahead of time.
    - Space them out throughout the day and week. You do not have to do everything in one day.
    - Whenever you can, sit to work or do daily chores.
    - Keep things you use the most within reach.
    - Prepare bigger meals and freeze portions to save preparing meals another day.

CONSERVE YOUR ENERGY (cont'd)

- Use things that help conserve energy.
    - Choose clothes that have zippers instead of buttons. Make sure the zipper is in the front and not the back.
    - Use long-handled grabbing tools to make reaching easier.
    - If needed, use a walker, shower chair, a bedside toilet, or raised toilet seat.
    - Choose lightweight household or kitchen items.
- Avoid things that drain energy, such as:
    - Doing chores or activities right after you eat.
    - Doing intense physical activity (such as shoveling snow).
    - Lifting, pushing, pulling or any other strenuous arm movement.
- Ask for help.
    - Ask those you live with to share in doing the daily tasks and household chores.
    - Ask family and friends to help out.

GET ENOUGH SLEEP

- Practice good sleep habits.
    - Have a regular bedtime.
    - Relax before bedtime.
    - If you cannot get to sleep within 30 minutes, try going to another room to read or watch TV.
    - Only use your bed for sleeping and intimacy.
- If you get short of breath lying down, prop yourself up with pillows. Please ensure to report this to your healthcare team if it happens.
- If you get up often to go to the toilet in the night, talk to your healthcare provider. Your medications might need adjusting.

THE BASICS OF MANAGING YOUR HEART HEALTH

The information in this section is intended to provide some general guidelines for patients whose heart is affected by amyloidosis. Your healthcare team will work with you to develop an individualized plan.

The symptoms you experience will influence your personal management plan. You might be surprised to know that YOU are the key player in your day-to-day care! Your healthcare team will guide your steps but you are in charge of how you handle things on a daily basis. This means keeping an eye on your symptoms and how you are feeling, plus learning how to manage your own condition.

This section of this booklet will cover:

- Monitoring symptoms that are related to how your heart is working
- Weighing yourself to make sure that fluid is not building up in your body
- Keeping track of sodium (salt) and fluid intake
- Learning the importance of having good overall nutrition
- Understanding how to watch potassium intake—only if this is something your health care provider has indicated needs to be done
- Preparing for medical appointments

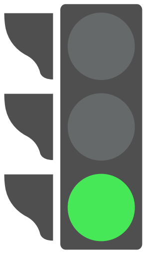
The chart information on the following page has been adapted from the Canadian Heart and Stroke Foundation. The Heart and Stroke Foundation is a trustworthy organization that helps Canadians who have heart disease and their families. It also supports healthcare professionals. Let's get started on talking about helpful things you should do daily to monitor your heart health.

At the end of this booklet, you will find a variety of worksheets you might like to use to track things like your weight, symptoms, blood pressure, medication, and exercise/activities.

Self-Monitoring Symptom Tracker

Use this tool to help monitor your ongoing heart health and any changes to symptoms.

HEART FUNCTION ZONES



THE SAFE ZONE

Your symptoms are under control.

- ✔ no new or worsening shortness of breath
- ✔ no changes to your activity level
- ✔ no new swelling in legs, feet or ankles
- ✔ weight is stable. Wt ____
- ✔ no pain, tightness, pressure in chest

THE CAUTION ZONE

Your symptoms are beginning to change and should be reported.

- ▲ some shortness of breath with activity or when sleeping
- ▲ dry, hacking or productive cough
- ▲ swelling in legs, feet, ankles or abdomen
- ▲ weight gain of more than 2 kg (4 lb) in two days, or more than 2.5 kg (5 lb) in one week
- ▲ sometimes feel dizzy or lightheaded but goes away with rest
- ▲ chest pain, pressure or tightness that goes away with rest or prescribed medicine

Contact your healthcare provider as you may need a change to your medications.

THE DANGER ZONE

Your condition has changed. Action is needed.

- ⊘ shortness of breath now happens at rest, can't catch your breath
- ⊘ frequent dry, hacking, productive or blood-tinged cough
- ⊘ severe swelling of legs, feet, ankles or abdomen
- ⊘ weight gain has been severe and sudden
- ⊘ severe dizziness, lightheadedness, fainting or confusion
- ⊘ chest pain, pressure or tightness, racing heart that does not go away with rest or prescribed medicine
- ⊘ cannot sleep flat (unable to lie flat); need extra pillows or sit up in chair to sleep

Warning Alert!

You need to be checked out NOW.
Call your healthcare provider, call 911, proceed to Emergency.

DAILY WEIGHT INFORMATION

CHECK YOUR WEIGHT EVERY DAY

Why?

- Excess fluid buildup in your body makes your heart work harder.
- Checking your weight every day lets you know if your body is retaining fluid.

When you report weight gain early to your healthcare provider, they can help you prevent your heart problem from getting worse. This may help prevent a trip to the emergency room or hospital stay.

When?

- Same time every day.
- Preferably before breakfast.

How?

- After you have emptied your bladder.
- Wear the same amount of clothing. Consistency is important.

If your weight increases by

- More than 2 kg (4 lb) in two days, or
- More than 2.5 kg (5 lb) in 1 week

call your healthcare provider. This weight gain means you are retaining fluid.

**For more information, please refer to 'Heart Function Zones' on page 29.*

RECORD YOUR WEIGHT EVERY DAY

Recording your weight every day is important so you can watch how this might change over time. Sudden changes in weight can give clues about how well your heart is working and if you are carrying extra fluid.

There are several ways you can track your daily weight. You may wish to use a calendar, the worksheet on page 67, or a notebook or computer. Remember to take your weight recordings to all healthcare appointments.

> ***ADVICE FROM A NURSE:***
>
> ***Even though it sounds simple, weighing yourself every morning is actually one of the easiest and best ways to watch for fluid buildup in your body.***
>
> *Lyndsay, Calgary, Alberta*

FLUID INTAKE WHEN YOU HAVE HEART PROBLEMS

What is a fluid?

A fluid is any food or drink that is liquid at room temperature. This includes water, ice, milk, juices, soft drinks, hot drinks, alcohol, soups, gelatin desserts, ice cream, popsicles, and liquid nutrition supplements (such as Ensure®, Boost®, or protein drinks).

Why do you have to be careful with fluid intake?

When your heart is not working as it should, fluid can build up causing swelling in your feet, legs or belly making your heart work harder. Fluid can also build up in your lungs, which may cause you to have trouble breathing.

On the other hand, not drinking enough fluid can be harmful to your health and cause heart and blood pressure problems.

How do you know when you have too much fluid?

To keep track of whether your body is holding on to too much fluid, weigh yourself daily.

You are holding on to too much fluid when:

- Your weight increases by more than 2 kg or 4 lb in two days
- Your weight increases by more than 2.5 kg or 5 lb in a week

* *Contact your healthcare provider right away if you are retaining too much fluid*

How much fluid can you have in a day?

You should have approximately 1.5 to 2 litres (6 to 8 cups, or 48-64 ounces) of fluid in a day. You may find you are thirsty to begin with. As you gradually reduce your fluid intake, your body will adjust!

If you are drinking far less than 1.5 litres (6 cups, or 48 ounces) of fluid in a day, you may need to drink a bit more.

The recommended amount of fluid a person should have per day can vary depending on their condition. Talk with your healthcare provider about how much fluid is recommended daily for you.

TIPS FOR REDUCING YOUR FLUID INTAKE

- Use smaller mugs and glasses. If you don't have smaller mugs or glasses, then reduce the amount you put in them or reduce the number of times you fill them in a day
- Measure the amount of fluid your mugs and glasses hold. They may measure more than 250 ml or 8 ounces

GUIDE TO FLUID MEASURES				
2 tablespoons	=	30 ml	=	1 ounce
1 cup	=	250 ml	=	8 ounces
1 pint	=	500 ml	=	16 ounces
1 litre or 1 quart	=	1000 ml	=	32 ounces
2 litres	=	2000 ml	=	64 ounces

**Total amount of fluid per day 1.5 to 2 litres = 48-64 ounces = 6-8 cups*

TIPS FOR REDUCING YOUR FLUID INTAKE (cont'd)

- Sip your fluids slowly.
- Write down the amount you drink each day until limiting your fluid becomes a habit.
- Sip your fluids throughout the day. Keeping track of how much fluid you ingest is the only way to learn how to make the 1.5 to 2 litres (6 to 8 cups, or 48-64 ounces) of fluid last you through the day.
- You may find it easier to use a reusable water bottle. Measure how much the bottle holds so you know exactly how much water you are drinking.
- Drain the fluid from canned fruit.
- Be aware of foods with high water content like watermelon, yogurt, and pudding.
- Swallow your pills with a small amount of soft food like yogurt or porridge if it takes a lot of water to normally get your pills swallowed.
- Limit the amount of sodium you eat to 2000 mg or less each day. Salt will make you thirsty. For more information, refer to page 34 on "Limiting Salt (sodium) When You Have Heart Problems".
- For some people, eating foods high in sugar (like desserts or sweet treats) makes them quite thirsty. Be mindful if this happens to you so you can monitor your fluid intake. If you have diabetes, controlling your blood sugar also helps control your thirst.
- Try not to drink alcohol. Alcohol dehydrates your body and makes you thirsty. It may also be harmful to your heart, and interfere with some of your heart medications.

TIPS TO DEAL WITH THIRST

- Rinse your mouth with water often, but do not swallow.
- Brush your teeth often.
- Use a mouth wash. However, do not use a mouth wash that contains alcohol. They tend to dry out your mouth.
- Snack on a small piece of cold or frozen fruit such as a frozen grape or cold orange slice. Try cold crisp vegetables too.
- Chew sugar-free gum.
- Suck on a lemon wedge, lemon candy, or sour candy.
- Use lip balm to keep your lips from drying out.
- Don’t overheat your home. Consider using a humidifier to increase the moisture in the air.
- Ask your pharmacist about gels or sprays that can add moisture to your mouth.

TIPS FOR THOSE THAT NEED TO INCREASE THE AMOUNT OF FLUIDS THEY TAKE IN

- Keep a glass of water at your side during the day and try to drink at regular intervals (such as a few sips every 15 minutes or so).
- If you don’t like the taste of water, you can try to add a lemon wedge or some cucumber slices to your water to change the flavour.
- Set a timer for regular times during the day so when the timer goes off you take a drink.

WHAT TO DO IF YOU ARE SICK

If you are feeling unwell and having any vomiting or diarrhea, or have been excessively sweating, you may have to relax your fluid restriction to keep yourself hydrated. Some of your medications may also need to be adjusted to prevent dehydration. Please contact your healthcare provider to discuss a “sick day plan”.

The last section (page 71) of this booklet contains a SICK DAY PLAN worksheet that you can take to your healthcare team at a regular appointment so that you have guidance on what to do should you get sick.

> ***ADVICE FROM A PHARMACIST:***
>
> ***If you are ever unsure about what type of medications you are taking, or what they are for, please talk to your regular pharmacist. They can help you with sick day management as well.***
>
> *Kendra, Saskatoon, Saskatchewan*

LIMITING SODIUM (SALT) WHEN YOU HAVE HEART PROBLEMS

(Adapted from Heart and Stroke Foundation– Living with Heart Failure)

Sodium is a mineral found in all forms of salt. This includes table salt, sea salt and kosher salt. Your body needs some sodium, but too much sodium causes your body to hold on to (or retain) fluid. It is important to know that the body processes all kinds of salt in the same way. One type of salt is not “better” than another. What you choose to use is up to you.

Extra fluid build-up makes your heart work harder. The fluid build-up can cause swelling in your feet, legs, or belly. Fluid can also build up in your lungs, making it hard for you to breathe. For these reasons, sodium intake needs to be reduced and maintained at a healthy amount for your body because the amount of salt in your body is directly related to the amount of fluid in your body.

KEEP YOUR SODIUM INTAKE TO LESS THAN 2000 MG EACH DAY

This means the amount of sodium from all sources including salt that is naturally within foods and salt that is added to processed foods or when cooking or at the table. One level teaspoon of table salt contains about 2000 mg of sodium. As you gradually reduce the amount of salt you are eating, your taste buds will adjust!

In the average Canadian diet, where does sodium come from?

- In ready-made processed foods and restaurant meals (77%)
- Naturally occurring in food (12%)
- Added to food in cooking and at the table (11%)

How to avoid salt (sodium)?

- Read nutrition labels to see how much sodium is in the product you are eating. A dietitian can help you figure out how to read the label if you are unsure how to understand the information on the label. Foods may contain a lot more salt than you think, even if they do not taste salty.
- Eat fresh foods most of the time and prepare home-cooked, low sodium meals.
- Frozen foods are acceptable if they do not have added salt or sodium additives (which are used as preservatives).
- Remove the salt shaker from the table. Don’t add salt, flavoured salts, or seasonings high in sodium to your foods. Remember that 1 teaspoon of salt contains about 2000mg of sodium!
- Season your food with herbs, spices, lemon juice, dry mustard, and garlic. Try one of the many seasoning blends which contain no salt such as Mrs. Dash®.
- Ketchup and some mustards are quite high in salt so try to limit the quantity of these in what you eat.
- Stay away from eating:
  - Processed foods
  - Deli meats
  - Pickled foods
  - Salted snack foods such as potato chips, pretzels, dips, and salted nuts
- Limit the amount of canned foods you eat. Choose products labeled ‘low sodium.’ However, foods labeled ‘lower’, ‘less’, or ‘reduced in salt or sodium’ may still be high in sodium (including soups and meats). Read the label of the “low-sodium” product compared with the label of regular product to see if there is a difference in the total sodium per serving.
- Eat out less often.
- Ask restaurants to provide information on low sodium choices.
- Restaurant meals and fast foods are always higher in salt than home cooked low sodium meals.

KEEP YOUR SODIUM INTAKE TO LESS THAN 2000 MG EACH DAY (cont'd)

How do I know how much sodium is in food?

Here are some helpful tips when reading the nutrition label:

- Look at the serving size—the amount of sodium listed is per serving (not the whole package)
- Keep track of the total amount of sodium you eat—remember: your maximum recommended daily amount of sodium is no more than 2000 mg per day from all sources
- Keep the sodium content of each meal below 650mg—this helps spread out your sodium intake over the day preventing excessive thirst and/or fluid retention
- By law, foods labelled ‘low sodium’ must contain 140mg or less per serving

Other ingredients high in sodium include:

Baking soda, brine, monosodium glutamate (MSG), soy sauce, fish sauce, garlic salt, celery salt, or any ingredient with ‘sodium’ as part of its name. Garlic powder is a good alternative to garlic salt. Sometimes there are similar substitute products that add the flavour you want without the sodium.

Processed Foods

Please look at the table on the bottom right side of this page. Does it surprise you to see the change in sodium content of foods once the food is processed?

Can I use salt substitutes?

Some salt substitutes use potassium instead of sodium. Check with your healthcare team or dietitian before using a salt substitute because some people need to limit how much potassium they have each day. If your healthcare professional has not told you to watch your potassium intake/levels, you do not have to worry about the salt substitutes.

<table>
<tr><th colspan="4">NUTRITION FACTS</th></tr>
<tr><td colspan="4">Serving Size Per 1/2 cup (125 ml)</td></tr>
<tr><th colspan="2">Amount</th><th colspan="2">% Daily Value</th></tr>
<tr><td colspan="2">Calories</td><td colspan="2"></td></tr>
<tr><td colspan="2">Total Fat 0.5g</td><td colspan="2">1%</td></tr>
<tr><td colspan="2">Saturated Fat 0.2g</td><td colspan="2"></td></tr>
<tr><td colspan="2">+ Trans Fat 0g</td><td colspan="2">1%</td></tr>
<tr><td colspan="2">Cholesterol 0mg</td><td colspan="2">0%</td></tr>
<tr><td colspan="2">Sodium 390mg</td><td colspan="2">16%</td></tr>
<tr><td colspan="2">Total Carbohydrate 28g</td><td colspan="2">9%</td></tr>
<tr><td colspan="2">Dietary Fibre 5g</td><td colspan="2">20%</td></tr>
<tr><td colspan="2">Sugars 9g</td><td colspan="2"></td></tr>
<tr><td colspan="2">Protein 7g</td><td colspan="2"></td></tr>
<tr><td>Vitamin A</td><td>2%</td><td>Vitamin C</td><td>0%</td></tr>
<tr><td>Calcium</td><td>8%</td><td>Iron</td><td>15%</td></tr>
</table>

UNPROCESSED	PROCESSED
Cucumber 7 slices = **2mg**	*Dill pickle* 1 medium = **569mg**
Chicken Breast 3oz = **74mg**	*Chicken Pie* 1 serving frozen = **889mg**
Tomato 1 small = **14mg**	*Tomato Soup* 1 cup = **960mg**
Pork Tenderloin 3 oz = **58mg**	*Ham* 3oz = **1095mg**

EATING TO PROMOTE GOOD HEALTH

Good nutritional habits are important because food is fuel for your body. Nutritional (or health) goals are designed to keep your body as strong as possible and to help you maintain a good quality of life. Some symptoms of cardiac amyloidosis such as weight loss, poor appetite, feeling full after eating a small meal may require special advice from a dietitian. If your area has a community Registered Dietitian you can ask your healthcare provider for a referral to see one.

General nutrition suggestions for people receiving treatment for amyloidosis:

- **Maintain your health and weight.** For many people, this means eating a variety of foods and enough calories every day to maintain your health and weight. It's important to get advice and support from your healthcare team to address any challenges you are having with eating during treatment.
- **Eat foods that promote health as often as you can.** These include lean meats and meat alternatives (like lentils, chickpeas or tofu), fibre and vitamin rich foods such as whole grain breads and cereals, vegetables and fruit, low fat dairy products, and heart healthy fats including small amounts of nuts, soft margarines and oils. A dietitian is the best person to talk to about which oils you should use.

Please ask your healthcare team for a referral to a dietitian if you would like to see one. Remember that nutrition goals and suggestions vary for each person, so there is not a "one-size-fits-all diet" for people with heart conditions. If eating or preparing meals is a struggle for you, this can result in poor nutrition that can cause problems with your heart health and overall well-being. A dietitian will work with you to find ways to improve your nutrition and health.

> ***ADVICE FROM A REGISTERED DIETICIAN:***
>
> ***"Limit sodium (salt) by using less packaged foods and condiments. Read labels and look for items that have a Daily Value of less than 5% for sodium. Add flavour to your cooking with things like citrus, herbs, garlic and ginger. Don't forget to bring joy to cooking by trying new recipes or flavours and cooking with a friend or family member!"***
>
> *Tiffany, Registered Dietitian in Calgary, AB*

WHAT ABOUT POTASSIUM?

Not everyone with heart problems has to worry about their potassium. But if you are someone that does need to pay attention to this, you need to know that both high and low potassium levels in the blood can cause problems.

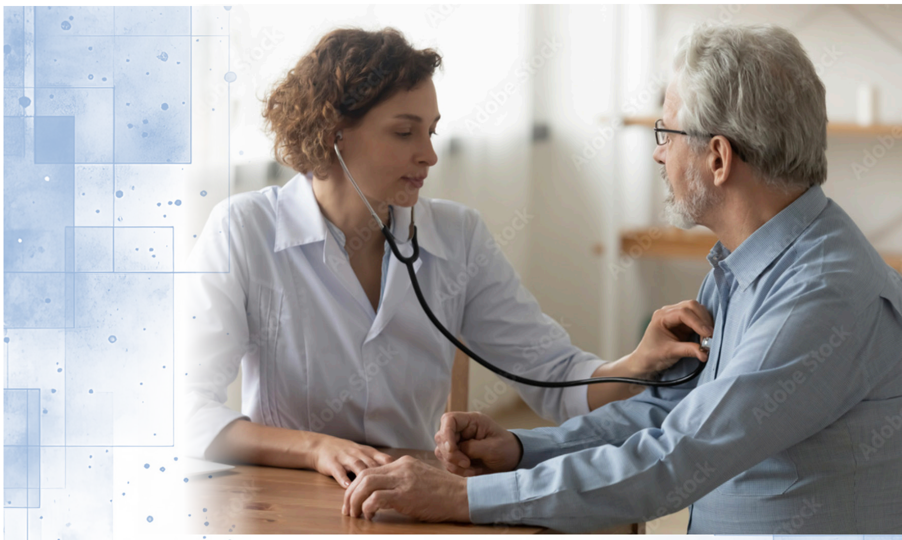
The heart is especially sensitive to high and low levels of potassium. High potassium levels (hyperkalemia) or low potassium levels (hypokalemia) affect how the heart beats—called the heart rhythm—and it can also affect how other muscles work in your body.

Some situations that can impact potassium balance in your body include: kidney problems, certain medications, vomiting, diarrhea and intake of certain foods.

If you do need to monitor your potassium intake, a registered dietitian can provide you with guidance on what foods and products contain high amounts of potassium.

PREPARING FOR MEDICAL APPOINTMENTS

It is very important to keep all medical appointments for health care professional visits or for testing or laboratory appointments. If for some reason you cannot attend an appointment, contact the appointment office and let them know you need to reschedule.



There are a number of things you can do to make the most out of appointments.

- Before the appointment, write down any questions you have and write down any changes to your health since your last appointment. This will ensure you don’t miss communicating something important with your healthcare team.
- Take any health monitoring sheets with you to your appointment. This can include the worksheets from the back of this booklet or a record of your weights, blood pressure, or other items.
- If you haven’t already done so, plan to discuss a sick day plan with your healthcare team. You may wish to take the page from the back of this booklet for them to fill in.
- Take your current medications, including over-the-counter medications, prescribed medications, supplements and herbal products with you. Alternately, you can take a written or typed list with you so long as it is complete and up to date.
- Pack a snack and water if your appointment is around mealtime or if you are unsure how long the appointment will be.
- Get plenty of rest prior to your medical appointments and tests.
- Consider having someone drive you to your appointment if possible. In this way you can be dropped off right at the door of the building and you do not have to worry about parking.
- Try to take notes about what is being talked about at appointments. Ideally, if you take a family member or friend with you then that person can take notes for you. In this way you will have a record of what was said in case you forget or in case you would like to share the information with other family members.
- Always ask for clarification if there is something you do not understand.

EXERCISE & ACTIVITY

With any heart condition, it is common to experience an impairment in how the body functions. Heart conditions can impact both your physical and emotional health. It is important to know that a diagnosis of amyloidosis doesn't mean you can't be physically active. What it does mean is that you may have to gradually increase your activity and keep an eye on how your body responds to it. Avoid inactivity as much as possible. The goal is to try and get back to normal activities as soon as possible following diagnosis.

ACTIVITY VERSUS EXERCISE

People often use these two terms to mean the same thing but they are different. Physical activity is when you are using energy to move your body to get from place to place. Exercise is a type of physical activity. Exercise is over and above the physical activity you get by just doing tasks you normally do. We exercise to improve or maintain fitness and health.

WHY ACTIVITY AND EXERCISE ARE IMPORTANT

Exercise is a planned physical activity. All types of exercise involve increasing the heart rate and strengthening muscles. Exercise is intended to improve or maintain fitness or health.

Keeping active is one of the best ways to keep healthy. Any amount of activity is better than none at all. No matter your age, or what health conditions you have, activity and exercise can help you:

- Sleep better
- Feel less tired
- Feel less breathless
- Feel more confident and in control
- Lower blood pressure
- Strengthen muscles and bones
- Reduce stress and tension
- Reduce feelings of anxiety or depression

Studies show that daily activity is good for you. It can help you to live better and longer.

GETTING STARTED

- Always check with your healthcare provider first before starting an activity to make sure you find an activity that matches your personal needs and ability.
- Start off slowly and pace yourself.

WHAT IF YOU DON'T FEEL CONFIDENT DOING ACTIVITIES OR EXERCISES ON YOUR OWN?

There may be community-based programs in your area that are designed for people with heart disease. For example, Cardiac Rehabilitation is a program specifically designed to improve the activity and exercise levels of people with heart conditions. Other types of programs may also be available and often these programs offer supervised exercise with exercise specialists in attendance. You may feel more comfortable exercising in this type of setting.

Sometimes these programs or therapists/specialists can set up a home-based program for you. A referral from one of your healthcare team members may be needed to attend a cardiac rehabilitation program or to see a physical therapist or exercise therapist. Sometimes there are costs for certain programs. Talk to your healthcare team members to see what options are available to you in your area.

TIPS ABOUT EXERCISE AND ACTIVITY

- Many of the day-to-day tasks around your house count as activity.
- If you are adding exercise to your routine, try to stick with it so that it becomes a regular habit.
- Consider wind and weather if you are doing an activity outside.
- Wear comfortable clothing and supportive footwear that matches the activity and weather. Make sure you are wearing something on your feet that does not slip off easily so that it becomes a risk for tripping.
- Count the fluids you drink during the activity as part of your daily fluid amount.

CHOOSING AN ACTIVITY THAT IS RIGHT FOR ME

It is important you feel comfortable doing the activity. Get to know your body. As long as you can talk without being short of breath, the level of activity is okay. If you are short of breath, either slow your pace or reduce the amount of time doing this activity.

WHEN TO STOP AN ACTIVITY

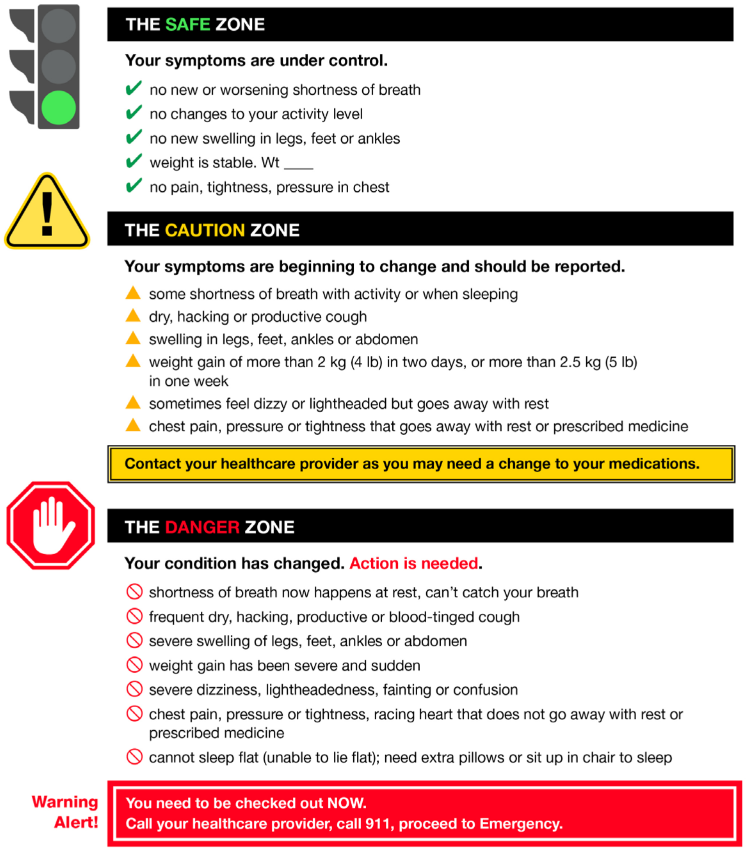
Stop the activity if you:

- Cannot carry on a conversation, sing, or whistle without being short of breath
- Feel weak, tired, or dizzy
- Feel sick to your stomach (nauseated)
- Feel your heart is pounding or racing
- Feel your heart beating irregularly and this is new for you
- Have pain in your chest, neck, jaw, arm, or shoulder

Stop the activity and rest. Sit in a comfortable chair. Once you feel the symptoms have gone away you can slowly go back to light activity. If the symptoms do not go away within a short period of time, call 911 and get to a hospital immediately. If the symptoms do go away but seem to happen on a regular basis when you are active, report this to your healthcare team.

BALANCE ACTIVITY AND REST

- Be active at a time when you feel rested and have more energy, such as first thing in the morning or after a nap. Some people find that it takes a while to loosen up in the morning so for those people exercise might be better suited to mid-morning. You will need to decide what is right for you.
- Choose which activities to do each day.
- Spread your activities throughout your day.
- If you are tired after an activity or the next day, then you have tried to do too much. Cut back a little on the amount of exercise and take things more slowly.
- It may take your body a while to find a balance between activity and rest, so do not give up.
- You should feel “back to normal” after 15 to 30 minutes of rest after exercise.
- Do not exercise to the point where you feel symptoms in the Red part of the Heart Function Zones (see chart below, also found on page 29), or above Level 5 Zone in the chart on the next page.
- Stick with it! It may take a while to see or feel benefits and find a routine.



THE SAFE ZONE

Your symptoms are under control.

✔ no new or worsening shortness of breath
✔ no changes to your activity level
✔ no new swelling in legs, feet or ankles
✔ weight is stable. Wt ____
✔ no pain, tightness, pressure in chest

THE CAUTION ZONE

Your symptoms are beginning to change and should be reported.

▲ some shortness of breath with activity or when sleeping
▲ dry, hacking or productive cough
▲ swelling in legs, feet, ankles or abdomen
▲ weight gain of more than 2 kg (4 lb) in two days, or more than 2.5 kg (5 lb) in one week
▲ sometimes feel dizzy or lightheaded but goes away with rest
▲ chest pain, pressure or tightness that goes away with rest or prescribed medicine

Contact your healthcare provider as you may need a change to your medications.

THE DANGER ZONE

Your condition has changed. Action is needed.

⊘ shortness of breath now happens at rest, can’t catch your breath
⊘ frequent dry, hacking, productive or blood-tinged cough
⊘ severe swelling of legs, feet, ankles or abdomen
⊘ weight gain has been severe and sudden
⊘ severe dizziness, lightheadedness, fainting or confusion
⊘ chest pain, pressure or tightness, racing heart that does not go away with rest or prescribed medicine
⊘ cannot sleep flat (unable to lie flat); need extra pillows or sit up in chair to sleep

Warning Alert!

You need to be checked out NOW.
Call your healthcare provider, call 911, proceed to Emergency.

Heart Function Zones – look for this resource on page 29

Activities most people with amyloidosis can do include the following:

- Walking
- Light housework
- Gardening
- Light vacuuming
- Stretching
- Laundry
- Grocery shopping

ACTIVITIES MOST PEOPLE WITH AMYLOIDOSIS SHOULD NOT DO

It is wise to avoid activities that involve working above your head for extended periods of time such as painting or washing walls, washing windows, vacuuming curtains.

Do not try lifting or pushing heavy objects, including shoveling heavy snow, or operating snow blowers.

HOW HARD TO EXERCISE

- Get to know your body.
  Pay attention to how exercise makes you feel.
- Use this table as a way to measure your effort.
- Aim to stay within the 3 to 5 scale during your exercise.

Rate your exercise effort		Talk test
0	Nothing at all	Resting
0.5	Very, very easy	Sing - you have enough breath to sing
1	Very easy	
2	Easy	
3	Moderate	Talk - you have enough breath to carry on a conversation
4	Somewhat hard	
5	Hard	
6		Gasp - you cannot say more than 4 to 6 words without gasping
7	Very hard	
8		Gasp - you cannot say more than 2 to 3 words without gasping
9	Very, very hard	
10	Maximum	You cannot talk at all

TYPES OF EXERCISE

Some exercises focus more on increasing the heart rate and blood flow.
Others focus on increasing strength. Many exercises are a combination of both.

Aerobic exercise

Any steady activity that increases your heart rate for at least 10 minutes is an aerobic exercise. Sometimes people refer to this as cardiovascular exercise (or ‘cardio’) meaning heart, ‘vascular’ meaning blood flow.

Examples of aerobic exercise include: walking outside or on a treadmill, using an exercise bike or swimming.

Aerobic exercise improves your body’s ability to use oxygen and helps your heart function at its best. Over time, your heart will not have to work as hard as it did. Hopefully you will be able to do more and feel better!

Strength exercise

Any time you contract a muscle using a weight or gravity it is a strength exercise.

Adding strength exercises to your activities can improve your overall fitness.

Examples of strength exercise: doing wall push-ups, doing leg lifts, using resistance tubing, lifting free-weights.

GETTING STARTED with EXERCISE

- Always check with your healthcare provider first before starting an exercise routine.
- Choose an exercise you enjoy.
- Start at a level that is right for you and do not be hard on yourself if you have to start with short exercise sessions, or exercise sessions that others think are too easy.

Check your Heart Function Zone before you start every exercise session – see page 29 of this booklet

- Exercise only if you are in the ‘Green Zone’.
- Start slowly with what you can do (not what you think you should do) and pace yourself.
- Aim to exercise most days of the week.
- Take rest breaks when you need them.

STARTING AEROBIC EXERCISE

Step 1: Warm up

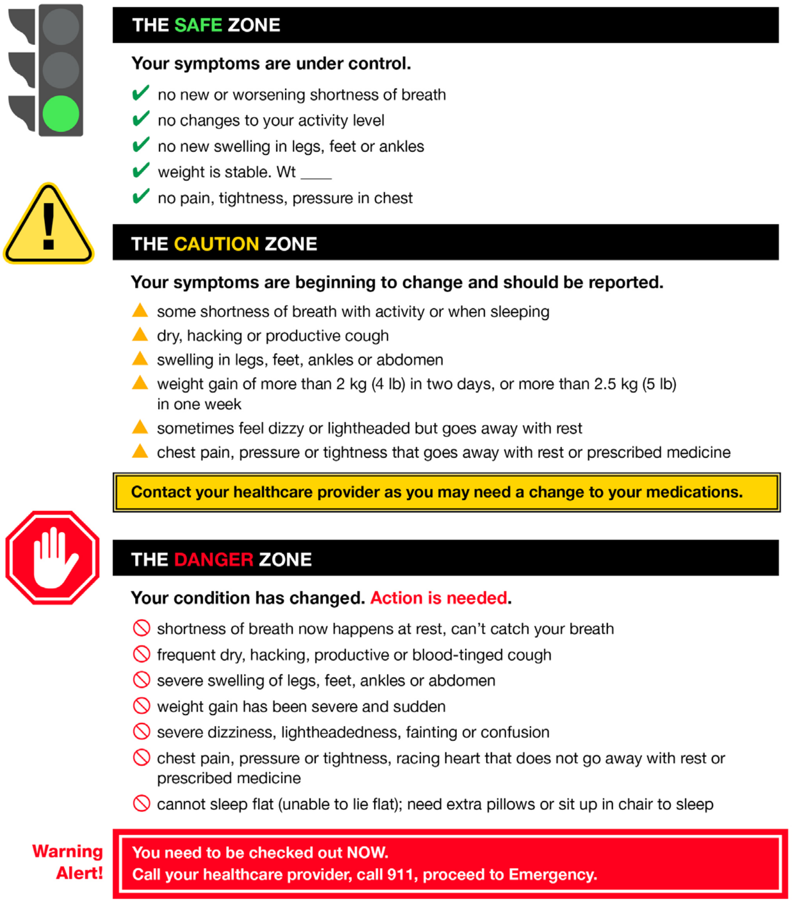
Take at least 5 minutes to warm up. This prepares your heart and body for the extra work. A good way to warm up is to walk or cycle slowly for 5 minutes.

Step 2: Condition yourself

Gradually increase the exercise to a steady, moderate pace. At first, aim for continuous exercise for up to 30 minutes, including warm up and cool down to start. Then work upwards so that your active exercise time is 30 minutes (excluding warm up and cool down).

Step 3: Cool down

Take 5 to 10 minutes to slow down your exercise rather than stop brisk activity suddenly. This helps your heart slowly return back to your resting heart rate.



THE SAFE ZONE

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✓ weight is stable. Wt ____
✓ no pain, tightness, pressure in chest

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Contact your healthcare provider as you may need a change to your medications.

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⊘ severe dizziness, lightheadedness, fainting or confusion
⊘ chest pain, pressure or tightness, racing heart that does not go away with rest or prescribed medicine
⊘ cannot sleep flat (unable to lie flat); need extra pillows or sit up in chair to sleep

Warning Alert!

You need to be checked out NOW.
Call your healthcare provider, call 911, proceed to Emergency.

Heart Function Zones – look for this resource on page 29

STARTING STRENGTH EXERCISE

It is best to have a cardiac rehabilitation professional help you start strength exercises. You will learn the proper way to do these exercises.

Generally:

- Choose 6 to 8 basic strength exercises for the larger muscle groups of both the upper and lower body
- Start with low resistance or light weights
- Repeat each exercise only 10 to 15 times
- Do your strength exercise routine 1 to 3 times a week with rest days in between

STARTING STRENGTH EXERCISE (cont'd)

REMEMBER—Call 911 if:

- You feel pressure or pain in your chest, neck, jaw, or shoulders that does not go away with rest or with nitroglycerin spray—if you have that prescribed for you
- You have a fast heartbeat that does not slow down with rest
- You feel like throwing up that does not go away with rest
- You feel your heart skipping beats and this is new for you, and it doesn't go away with rest
- You get a shock from your implanted heart device—implantable cardioverter (i.e., defibrillator or ICD)—if you have one

NEVER drive yourself to the hospital instead of calling 911.

TIPS FOR EXERCISE

- Stick with it, so it becomes a habit
- Schedule exercise sessions into your daily routine
- Exercise at a time of day you feel your best
- Include a variety of exercises so you do not get bored
- Wear comfortable clothing and supportive footwear that cannot fall off easily
- Choose to walk whenever you can instead of driving
- Choose the stairs instead of the elevator if you are able to
- Wait 1 hour after eating a meal to exercise
- Adjust your pace when walking in hilly areas
- Exercise indoors when it is too cold, too hot, or too humid outside
- Count the fluids you drink during the activity as part of your daily fluid amount
- Keep an exercise record. This helps you see your progress

ADVICE FROM CARDIAC REHAB STAFF:

"I believe exercise can provide some benefit to patients with cardiac amyloidosis. However, this benefit is not well documented in current literature, but I hope that with further research studies related to amyloidosis and exercise we can find evidence to support these benefits."

Dr. Aggarwal, Cardiologist and Medial Director for Cardiac Rehabilitation in Calgary, AB.

MENTAL AND EMOTIONAL HEALTH

**Your emotional health is a very important aspect of overall well-being.
Many people being treated for chronic health issues experience a range of feelings.
It is common to feel low, anxious, or depressed.**

This section will give you more information on how to recognize signs and symptoms of stress, anxiety, and depression. It will also give you helpful tips and ideas on how to manage these concerns.

PRACTICAL MATTERS

Feeling sad is a normal response to a health diagnosis, as is worrying about the future. Feelings can be challenging and may include anxiety, grief, guilt, uncertainty, anger, spiritual distress, fear, and feeling isolated or lonely. Worrying about treatment, its success and side effects, or changes in your physical health, lifestyle, and family dynamics can also impact your mental health. Knowing when to seek help from your healthcare team is important. They can refer you to someone who can help, such as a psychologist or mental health worker who specializes in caring for people with these concerns.

STRESS

WHAT IS STRESS?

Stress is your body's reaction to an event or situation (real or imagined).
Stress refers to how your body responds to a situation or event.
Too much stress is hard on your mind and body, especially your heart.

While stress is a part of everyday life, too much stress increases a person's chances of getting or worsening heart disease. High levels of stress or stress over long periods can cause:

- Increased blood pressure
- Increased heart rate
- Increased cholesterol
- Increased chances of having a heart attack or stroke

WHAT ARE STRESSORS?

A stressor is any situation or event that triggers your body's stress response. Stressors are different for each person. Examples of stressors:

- Receiving a new health diagnosis of heart failure or amyloidosis
- Limits in physical ability
- Having chronic pain
- Dealing with a number of health conditions at the same time
- Conflict in a relationship
- Being isolated from friends and family
- Dealing with the death or illness of a loved one
- Changes at work
- Money worries

STRESS (cont'd)

WHAT MIGHT HAPPEN IF YOU HAVE TOO MUCH STRESS?

Stress can affect your thinking:

- Trouble concentrating, short attention span, easily distracted
- Poor judgement
- Lapse in memory
- Difficulty making simple decisions
- Brooding over problems
- Imagining the worst
- Confusion

Stress can affect your behavior:

- Crying
- Fidgeting and pacing
- Having more arguments
- Drinking more coffee, tea, cola
- Withdrawing from others
- Overeating or loss of appetite
- Smoking
- Drinking alcohol or using other substances to "de-stress"
- Sexual difficulties

Stress can affect your emotions:

- Feeling helpless and frustrated
- Feeling overwhelmed by your life
- Feeling anxious or worried
- Feeling irritable, hostile, or angry
- Feeling down, depressed, or hopeless

Stress can affect your body:

- Headache
- Knots or feeling sick to your stomach
- Restlessness
- Sweating
- Increased heart rate and blood pressure
- Rapid, shallow breathing
- Muscle tension in jaw, neck, or shoulders
- Tremors in hands or legs
- Tingling or numbness in fingertips
- Trouble sleeping, feeling tired all the time

Sometimes when people feel very stressed and overwhelmed, they start to think about hurting themselves. If you have started to make a plan to hurt yourself, tell someone and go to the nearest emergency room right away.

ADVICE FROM A MENTAL HEALTH PROFESSIONAL:

> ***"It is very common to feel anxious and depressed following your diagnosis. The tips below are proven to help. If you are struggling, please reach out for mental health support. A mental health professional will listen without judgement, offer support that is right for you, and help you to overcome your fears."***
>
> *Dr. Vidya Raj, Psychiatrist with the Hearts and Minds Clinic in Calgary, AB*

SUGGESTED RESOURCES

- www.anxietycanada.com / Mindshift app – free Canadian Cognitive Behavioral Therapy (CBT) resource for anxiety
- There are many mindfulness apps to practice relaxation and meditation skills.
  - Free ones include Calm, Smiling Mind and Insight Timer.

TIPS TO MANAGE YOUR STRESS

- Practice deep breathing and other forms of relaxation such as:
  - Meditation, yoga, and stretching
- Call a friend or close relative
- Maintain healthy habits such as:
  - Exercising daily to get rid of tension
  - Eating a healthy diet to nourish your body
  - Getting a full night's sleep
- Limit what you take on. It is okay to say 'no'
- Make small changes to organize your life
- Use a calendar and a 'to do' list to help you manage your time
- Look for the good in yourself or others
- When a worry enters your mind, ask yourself if it is a problem you can solve. If the answer is yes, set aside some time to problem solve. If the answer is no, let the worry go!
- Have as much fun as possible. You deserve it!

ANXIETY

WHAT IS ANXIETY?

Everyone experiences anxiety at times. Anxiety is our body's natural response to a threat. This is sometimes called the 'fight-flight-freeze' response. Our body releases adrenaline in response to a real danger or to something that feels threatening or dangerous.

Our heart rate increases and blood shifts to our large muscles. All this prepares our body to respond to the danger by fighting, fleeing (flight), or freezing.

Often anxiety goes away once the threat is gone. Anxiety can become a problem when a person continues to have worried thoughts or reacts as if there is a danger when no real danger exists. You may notice anxiety in yourself or others may notice it in you.

WHAT CAUSES ANXIETY?

It is different for every person. Many situations can cause you to feel anxious, worried, or tense. There are things that can make your anxiety response worse:

- Certain medical conditions
- Stopping medicines on your own
- Substance abuse

You are more likely to feel anxiety if:

- You have a family history of problems with anxiety or depression
- You have an imbalance of certain chemicals in your brain

ANXIETY AND ITS AFFECT ON MY HEART HEALTH

The increased heart rate and blood pressure that anxiety can cause adds stress to your heart. Anxiety can increase your blood sugar and cholesterol. Anxiety can make it hard to sleep.

WHAT ARE THE SIGNS OF ANXIETY?

Many people do not recognize certain body responses as things that can be caused by anxiety. Instead, they think something is physically ‘wrong’ with them. Anxiety can affect your body, your thoughts, and your behavior.

Possible body responses:

- Fast, pounding heart
- Rapid breathing, shortness of breath
- Chest pain or discomfort
- Sweating
- Feeling dizzy or lightheaded
- Dry mouth, nausea, stomach upset
- Pale skin color compared to normal for you
- Muscle tension
- Trembling or shaking
- Numbness and tingling
- Hot or cold flashes
- Panic attacks

Possible thoughts:

- Having frightening dreams or thoughts
- Overestimating the chances something bad will happen
- Magnifying how bad the situation is or how bad a future situation will be
- Not believing you can cope
- Having trouble concentrating or making decisions

Possible behaviours:

- Using alcohol or drugs to lessen the anxiety
- Needing others to reassure you all the time
- Needing to be with a ‘safe’ person
- Staying away from certain places, activities, or people

WHAT CAN YOU DO WHEN YOU HAVE MILD ANXIETY?

Remember it is not unusual for someone with a heart condition to feel scared, worried, or tense. Included below are some ideas to help you deal with mild anxiety.

- Be aware of how you experience anxiety.
- Identify things that trigger your anxiety.
  - Ask yourself “Is this really a threat or a danger?”
  - Ask yourself if your worry is something you have some control over. If it is, try to resolve it. If it isn’t, let it go.
- Practice deep breathing and other forms of relaxation such as:
  - Meditation, yoga, stretching, praying, reading, going for a walk, listening to music.
- Eat a healthy well-balanced diet.

ANXIETY AND ITS AFFECT ON MY HEART HEALTH (cont'd)

WHAT CAN YOU DO WHEN YOU HAVE MILD ANXIETY? (cont'd)

- Get a good night's sleep
    - Limit caffeine containing products like coffee and chocolate during the day and avoid close to bedtime
    - Avoid energy drinks as they contain high amounts of caffeine
    - Avoid exercise close to bedtime
    - If watching the news at bedtime adds anxiety, don't watch it at that time
- Reduce stress in your life where you can
- Set a routine for doing daily activities
- Use a calendar and a 'to do' list to help you manage your time
- If you are having a bad day, talk to someone you can trust

HOW IS MODERATE TO SEVERE ANXIETY TREATED?

Anxiety disorders respond well to treatment. Treatment can include:

- Counselling
- Support group
- Behaviour therapy focusing on changing thinking and patterns of behaviour
- Exposure therapy focusing on facing the situation in a safe environment
- Medications prescribed by a healthcare professional

Sometimes when people feel very anxious and overwhelmed, they start to think about hurting themselves. If you have started to make a plan to hurt yourself, go to the nearest emergency room right away.

NEVER USE ALCOHOL, TOBACCO, OR NON-PRESCRIBED DRUGS
TO HELP YOU MANAGE YOUR STRESS or ANXIETY.

The Canadian-wide emergency mental health line can be reached by phoning 988

988 is available 24 hours, 7 days a week. Available in English and French.

DEPRESSION

HOW CAN DEPRESSION AFFECT YOUR HEART HEALTH?

Depression can make many health issues including your heart health worse. If you are depressed you will find it harder to do the things you need to do to manage your heart condition. Some examples of things that can be harder are exercising, eating properly, tracking your fluid intake, remembering to take your medicines and weighing yourself daily.

WHAT IS DEPRESSION?

It is a medical condition where a person feels sad, loses interest in daily activities, withdraws from people, and feels hopeless about the future. Depression is different from grief, sadness related to an event, or low energy. It stays with you and can become long lasting or chronic.

WHAT CAUSES DEPRESSION?

Depression may be caused by one factor or several factors. Some factors that might cause depression include:

- An imbalance in the natural chemicals in the brain
- Family history of depression
- Chronic health conditions

Depression can be triggered by difficult life events such as:

- Death of a loved one
- Divorce or separation
- Loss of a job
- Changes in overall health
- Childbirth
- Using alcohol or drugs
- Adjusting to a new home, community or country
- Being a care giver to someone living with a chronic health issue

Depression is not caused by a personal weakness.

SIGNS OF DEPRESSION

- Constantly feeling sad without a specific cause
- Feeling hopeless, guilty, or worthless
- Having little or no interest in people or activities you used to enjoy
- Feeling really tired or low on energy not due to another medical condition
- Sleeping too much or not sleeping enough
- Feeling like you are speeding up or slowing down
- Unplanned changes in your weight (weight loss or weight gain)
- Changes in your appetite
- Having trouble thinking, concentrating, or remembering
- Having trouble making decisions
- Thinking about hurting yourself or about dying

If you are experiencing any of the above, it is best to follow up with your healthcare provider. You may also visit the “Resources” section on page 63 for additional resources.

Sometimes when people feel very depressed and overwhelmed, they start to think about hurting themselves. If you have started to make a plan to hurt yourself, tell someone and go to the nearest emergency room right away.

DEPRESSION (cont'd)

HOW IS DEPRESSION TREATED?

It is essential to get medical treatment for depression. Some effective treatments include:

- Mental health counselling
- Medicines to improve mood
- Lifestyle changes such as exercise and proper sleep

IDEAS ON HOW TO MANAGE DEPRESSION

Set small goals:

- Set small self-care goals such as taking a walk, eating a well-balanced meal.
- Set small household goals such as doing the dishes, paying bills, taking care of work you have been avoiding.

Watch out for negative thinking:

- Be aware of your thoughts. Negative thinking is very common with depression.
- Ask yourself what you would say to a friend who had that negative thought.
- Try to be kinder to yourself.

Engage in problem solving:

- Identify and define problems.
- Make a list of possible actions to address the problem.
- Identify pros and cons for each action.
- Pick the best action and try it out.
- Think about how it went.
- Think about steps for solving problems that you have used before. Draw ideas from those steps.

Socialize and have fun:

- Reach out to friends and family.
- Make social plans and go even if you "don't feel like it".
- Make time for pleasant activities. You may need to gently force yourself to do these things. Don't wait until you want to or it may not happen!

If your mental or emotional health is causing a problem for you in any way, please let your healthcare provider know. A referral can be made to a professional for additional help.

Below are some suggested resources, including helplines and support offered via online chat. You may also visit the "Resources" section of this booklet on page 63.

Call 911 if help is required emergently.

Suicide Crisis Line—call or text 988 if you or someone you know is thinking about suicide. Help is available 24 hours a day, 7 days per week. Support is bilingual, trauma-informed, culturally appropriate and available to anyone in Canada.

The Indigenous Hope for Wellness Helpline 1- 855-242-3310 (toll free).
Help is available 24 hours a day, 7 days per week in multiple languages by phone or online chat.
https://www.hopeforwellness.ca

Get Help Canada—lists support by province
https://www.canada.ca/en/public-health/campaigns/get-help-here.html

The Canadian Amyloidosis Support Network https://amyloidosiscanada.org

Transthyretin Amyloidosis Canada https://madhattr.ca

Canadian Supports for Caregivers https://canadiancaregiving.org

Caregiver Resources—Canadian Centre for Caregiving Excellence
https://canadiancaregiving.org/resources/caregiver-resources/#National

SUPPORT FOR PATIENTS AND CAREGIVERS

Living with cardiac amyloidosis can be challenging, not only for those diagnosed but also for the loved ones who support them. Remember- it is not a weakness to need or ask for help.

SUPPORT GROUPS

Joining groups or networks offers a sense of community, shared knowledge, and emotional support, which can positively impact mental and physical health.

Talk to your healthcare provider for any local, regional, provincial, or national groups that you can join. Visit the “Resources” section on page 63 for additional information.

COMMUNITY RESOURCES

Each province and community will be different in the kinds of community resources available. Your healthcare providers should be able to direct you to community resources available.

COUNSELLING

Need someone to talk to? Community organizations may offer low-cost or sliding fee scales for individual and family counselling. You may have access to other types of counselling through your province or private health plan.

SPECIALIZED HEALTHCARE SERVICES

There may be a point of time when there is a need for more specialized medical care. This could include a geriatric or pain clinic, foot care services or mental health services. Referrals to community healthcare members like social workers, physiotherapists, occupational therapists, or registered dietitians may also be needed.

HOUSING OPTIONS AND HOME SUPPORT FOR THOSE LIVING WITH HEART PROBLEMS

It can be difficult to think about changing where you live. It may become necessary to down size your home or consider other housing options. This might include group homes, senior housing, or continuing care. Often, a person can remain safely in their own home with the help of home care and other community services.

An occupational therapist may be able to review your living situation and make suggestions on how to make it safer or easier for you to stay in your current home. This might include equipment in the bathroom. A physiotherapist may be able to provide support on maintaining strength and movement.

Some communities offer food and prescription delivery services. If this would be helpful, contact the businesses you usually use for advice.

FINANCIAL AND LEGAL MATTERS

Federal and provincial programs may offer some financial supports such as disability tax credit, family caregiver tax credit, and/or employment insurance benefits, and compassionate care leave. Subsidy and benefit programs may help you or your care recipient. It may be helpful to talk to a financial expert for help on these matters.

SUPPORT FOR PATIENTS AND CAREGIVERS (cont'd)

FINANCIAL AND LEGAL MATTERS (cont'd)

Seeking expert advice is also recommended for legal affairs. Some non-profit agencies may be able to assist but usually it is a lawyer who can best help with legal documents. These documents could include advance care directives/plans, power of attorney and wills. Please see the section on Miscellaneous Legal Matters (ADVANCE CARE PLANNING) on page 59 for more information.

RESPITE

If demands and the toll of caregiving become too much, it may be necessary to consider respite care. Respite gives caregivers some time off in order to prevent burn out or to reduce stress. Usually arranging respite care requires some advance planning. There are two common types of options—day programs and home care/long term care facility programs.

Day programs happen outside of your home. An agency in the community will care for your loved one for a portion of the day. Your loved one goes to the program and returns home each day.

Home care/long term care programs will provide care to your loved one that includes overnight stays. The length of time will be worked out between you and the agency.

TIPS FOR CAREGIVERS

When a person gets a diagnosis of amyloidosis, a family member or loved one often takes on the role of caregiver. Caregivers provide support in many ways. Often it is a mix of many different things, depending on the tasks needed. This may range from helping with day-to-day needs to attending appointments and understanding the healthcare system to making difficult decisions.

The role of a caregiver is a very big responsibility. It can present challenges for you and your loved one. It is not possible to cover all aspects of the role in this document, but here are a few things to consider.

☑ Educate yourself about amyloidosis

Start by learning the symptoms of cardiac amyloidosis, required tests and treatment. Proper information will help you understand what is going on with the person you care about. This information will help you to have better conversations with your loved one and their healthcare providers. This knowledge will equip you to handle the journey ahead and communicate during the process.

☑ Communicate openly and honestly with each other

This can help strengthen your relationship and can help you deal with tough days when or if they come. It is okay to ask, "What do you need me to do?" and, "How can I help you?"

It is okay to say – "I need some things from you too". Both the person living with amyloidosis and the care giver, plus other members of the family, will all have needs of their own. Try to work as a team.

☑ Work on a care plan together

A care plan is just a starting point. It will change as needs and the condition change. Encourage your loved one to do as much as possible for themselves. This might include taking responsibility for recording daily weights and blood pressure readings, ensuring medications are taken as directed, and helping with jobs around the home that do not cause a lot of fatigue. Do tasks together when reasonable. Your time and energy are important too.

☑ Let go when needed

You will not be able to control everything as that is not humanly possible. It may be that your loved one does not want to follow the management plan set up by the healthcare team. Try to express your concerns calmly and without arguing.

☑ Share Your Situation With Others

As a caregiver, adapting your schedule or routine is common. Open and transparent communication about your caregiving responsibilities promotes understanding and helps you find a balance between life and caregiving duties.

Here are some tips on discussing amyloidosis and your caregiving role:

a) Transparency—be candid with people in your life about amyloidosis and its effects

b) Request Flexibility—ask for flexibility in schedules when needed

c) Educate—share information about amyloidosis to foster empathy and cooperation

d) Plan Ahead—anticipate appointments and plan commitments accordingly

☑ Managing Healthcare Appointments

Prepare for medical appointments. Before the appointment, talk together about any new health changes or concerns. Write them down on paper to take with you. Also take all current medications, including over-the-counter and herbal medications with you. Pack a healthy snack and some water if the appointment is around your normal meal time. Be prepared to take notes at medical appointments as this can help with remembering what healthcare team members have said.

CAREGIVER SELF-CARE TIPS

Being honest about how you are doing plus building a strong support network can really help you on your emotional journey.

When caring for others, it is important to look out for you own well-being. Engage socially beyond caregiving, and maintain your health through exercise, rest, and a balanced diet. Take time for yourself to prevent caregiver stress or burnout. Know your own limits. Make time for activities that bring you joy.

Here are some more tips for taking care of yourself:

☑ Be Kind To Yourself

Adjusting to the new ‘normal’ can be extremely difficult. It often resembles a rollercoaster of emotions and overwhelming circumstances. Keep in mind, not everything is within your control. It’s essential to be realistic about your boundaries of what you can and cannot do.

☑ Enlist Help From Your Support Team

Handling everything alone can lead to burnout. This can affect both your mental and physical health. You need your own support system and personal care plan to get through difficult times. Consider the following ideas:

- Create a list of ways others can assist you, whether it’s picking up groceries or preparing a meal
- Seek support from family and friends—they can be a valuable source of encouragement
- Stay connected to others by maintaining connections with loved ones and/or social groups
- Share your feelings with someone you’re comfortable talking to about your situation—remember, you don’t have to face challenges alone—reaching out can make a significant difference
- Join a caregiver support group if there is one available in your area—if you are struggling, please reach out to your own healthcare provider; do not let your own needs go unattended

CAREGIVER WELL-BEING CHECKLIST

Adapted from: Caregiver Wellbeing Checklist (caregiversalberta.ca) / Adapted from the Resource Guide for Family Caregivers, Family Caregivers’ Network Society, 2006

Here are some suggestions for keeping up your strength and well-being as a caregiver. You may want to start with one item, then build up to a few more. Choose those you feel will benefit you the most. Remember that if you don’t reach your goal, there should be no guilt. The items you choose are goals to work toward as you are able. You may want to share these ideas with other family members or loved ones.

✔ I will try to get out or exercise at least twice a week. Even a walk is considered exercise
✔ I will try to get at least seven-to-nine hours of restful, sound sleep per night
✔ I will try to eat three balanced meals or four to five small, nutritional meals per day
✔ I will keep my regular dental and medical appointments
✔ I will try to keep up with my favourite hobby or special interest
✔ I will try to do something special for myself at least once per week
✔ I will try to talk with, or visit, up to three friends or relatives weekly
✔ I will try to attend a community caregiver group or support group if one is available, or speak to a friend or counselor about my feelings if I need to
✔ I will try to unplug from technology such as phones and computer for a set time each day to help me get in tune with my own emotions

Remember, caring for yourself is essential—it allows you to continue providing compassionate care to your loved ones. Some days or weeks may be harder than others. See each day as a new day to begin your efforts for selfcare.

SIGNS OF CAREGIVER STRESS

When you are focused on caring for someone else, you might not realize that your own health is suffering. At times you might feel overwhelmed – physically or emotionally. This is called caregiver stress.

Watch for these signs of caregiver stress:

- Feeling tired all the time
- Having trouble sleeping, experiencing nightmares or insomnia
- Gaining or losing a lot of weight
- Experiencing headaches, stomach aches, or other physical symptoms due to stress
- Feeling guilty; like you are not doing enough
- Feeling overwhelmed, irritable, frustrated or short-tempered
- Feeling emotional and moody; may include crying more often
- Having conflicts with the person you care for or with others close to you
- Losing patience with your family or pets
- Feeling you don't have time for yourself or to be with others
- Having no interest in doing activities you used to enjoy
- Using substances such as tobacco, alcohol, or non-prescribed drugs more often to help manage your feelings; taking non-prescribed medications to help sleep or improve your mood

Remember, recognizing these signs early allows you to seek support and prioritize self-care. Seeking help is a sign of strength.

Talk to your healthcare provider if you are feeling any of these symptoms. You may also wish to visit the 'Mental and Emotional Health' section on page 44, or the 'Resources' section on page 63.

Do not let your own needs go unattended. You are important!

TIPS FOR TRAVELLING WHEN YOU HAVE AMYLOIDOSIS

With careful planning, people with amyloidosis can travel safely.

PLANNING FOR TRAVEL

- Talk with your healthcare provider before you commit to any trip, especially if you have a pacemaker or implantable cardioverter-defibrillator (ICD). Changes in your daily life associated with travelling such as weather, diet and activity levels may aggravate symptoms of amyloidosis. Be sure to let your healthcare provider know well in advance when you are planning to travel, including where you are going, who you are travelling with, and for how long.
- Make sure your immunizations are up to date.
- Buy travel health insurance, especially when travelling outside of Canada and even if only for a day. Make sure it covers pre-existing illnesses and be aware of what your policy covers and does not cover.
- Consider buying cancellation insurance on flights and bookings in case you have a sudden change in your health.
- When flying, especially outside of Canada, you might need a travel letter from your doctor explaining why you need to travel with all your medications. Check with your travel agent or airline.
- Know where to go to get medical help when you get to your destination by finding out before you leave. Check to see if there is a hospital or medical clinic nearby.
- Pack a cell phone. Check with your cell phone provider to make sure you have coverage in the area you are travelling. It may also be possible to purchase a SIM card in the country you will be in, but this should be looked into before you leave home.
- If travelling to a different time zone, ask your healthcare provider if you should adjust your medication schedule.
- Consider wearing a Medical Alert bracelet or necklace.
- Carry paper copies of your medical information and also have copies on your phone such as:
  - A list of health and medical problems
  - A list of all your current medications
  - Results of recent blood tests
  - Names and contact phone numbers of your healthcare providers
- Take enough of each medication to last the whole trip plus extra, in case of an emergency or a travel delay. Some amyloidosis medications may require some additional planning in advance to get a longer supply to last you for the duration of your trip.
- Keep all your medications in the packaging supplied by the pharmacy.
- Consider asking your pharmacist to put your medications into 'blister packs' so you don't have to travel with all your original containers.
- Make sure each medication name is clearly marked—this is especially important when crossing borders.
- If possible, weigh yourself while you are traveling.

WHEN NOT TO TRAVEL

It is best to stay home if:

- Your healthcare provider has advised you not to travel
- You have recently come home from being in the hospital
- Your doctor has changed one or more of your medications, such as a change in dose or how often you take it
- You cannot get travel health insurance—recent hospitalizations or changes in your medications may make you ineligible for certain types of travel insurance
- You notice increased signs of heart issues (shortness of breath, weight gain, fatigue, cough, swelling in your feet or belly area, or dizziness)

TRAVELLING WITH A HEART DEVICE

- If you have a heart device (a pacemaker or an implantable cardioverter-defibrillator, ICD), check with your healthcare provider prior to leaving, especially if your device is being monitored remotely
- If you have just had a heart device inserted, wait until your first follow-up appointment to find out when it is safe for you to travel
- Ask your healthcare team for a copy of your heart device instructions in the language of the country you are travelling to. If this is not available, take the English copy with you
- Ask for a recent print-out of settings for your heart device
- If you have an ICD, ask what you should do if you get a shock while away
- Keep your cell phone at least 6 inches away from your heart device at all times (and not just when travelling)
- Always carry your heart device identification card with you
- When going through security:
    - Show your heart device identification card before going through the metal detectors
    - Know your heart device will likely set off an alarm when walking through an archway metal detector
    - Ask for a ‘hand check’ instead of a wand metal detector check. A wand metal detector could momentarily change the settings on your heart device

DURING YOUR TRAVELS

- When sitting for prolonged periods (such as time on a plane, train, or bus) get up to move or get out for a walk every 2 hours if possible.
- Talk to your physician or nurse practitioner about whether you should wear compression socks when travelling requires a lot of sitting or walking, or if you are travelling by plane.
- Whenever you must check your luggage, carry all your medications with you in a carry-on bag.
- Take your medications on schedule.
- It is best not to buy any medications in other countries. Ingredients can vary from what is in the medication from Canada.
- Be careful you don’t drink too much fluid. When in hot climates or when socializing, people tend to drink more.
- Watch your portion size for both meals and snacks. Eating more than normal can cause bloating, an upset stomach, and indigestion.
- Eat your largest meal either at lunch or earlier in the afternoon. Have a light dinner or early evening snack.
- Eating out usually means foods high in sodium. Whenever you can:
  - Ask for “no added salt”
  - Choose low calorie and low salt meals and snacks
  - Say “no thanks” to sauces, gravies, and prepared foods
  - Make your own low salt meals instead of eating out

Plan ahead. Travel safe. Enjoy!

ADVANCE CARE PLANNING

An Advance Care Plan will let people know what you would like done and not done for any future healthcare treatments. Sometimes the term "living will" is used in place of the term advance care plan. Advance Care Planning is wise to do because your amyloidosis may get worse over time.

While you may never need to use the plan, it is best written when you are healthy and before there may be an urgent healthcare need. An Advance Care Plan can be used for healthcare decisions, both now and in the future. You can always make changes to your Advance Care Plan as long as that is communicated to others.

It is recommended that adults who have chronic health condition(s) or who are of older age have a plan written down. Here are some reasons why:

- A documented plan will help state your wishes and what is important to you. If it is written down, no one can argue with what you meant
- It can bring you peace of mind knowing your loved ones and medical team can honour your wishes
- It can ease the stress of your loved ones to know you have made your own decisions
- If you are not able to speak your wishes (such as during a medical emergency), this document will act as your voice

Here are some of the decisions you need to make when putting a plan in place

- Who do you want to be your substitute decision maker if you cannot direct or communicate for your own care? If you have not put the name of this person in the document, decision making can get difficult. You need to assign one person for this role.
- How do you feel about resuscitation if your heart or breathing stops? Do you want life saving measures to be done?
- How do you feel about life support? Do you want the use of machines to keep you alive if you become critically ill?
- How do you feel about end-of-life care? What do you want done?
- How do you feel about organ donation at the time of passing?

Putting a plan in place requires a lot of thought. Even though it can be hard to talk about these things, it is good to include your loved ones in the conversation and planning. Your loved ones should also know where you keep the document. Making a copy of the plan and giving it to a family member or loved one is a good thing to do.

Should you require admission to a hospital, or care in an emergency department, you may be asked if you have an Advance Care Plan. It is your responsibility to keep the document up to date. If you change your mind on any of the details or your wishes, it must be added to the document to keep it current.

Different provinces and territories in Canada may have different ways of managing Advance Care Plans. Speak to your primary healthcare provider for more information or speak to a legal professional on how to document your plan.

ORGAN DONATION

Another topic you may want to consider when preparing your Advance Care Plan is organ donation. Organ donation can help save the lives of others by providing healthy organs to those in need. This is called an organ transplant. It can be a gift to someone who has limited chance of living without getting a new organ. Organ donation is very uncommon for those with amyloidosis because the disease affects many parts of their body, however certain organs/tissues may be eligible for donation.

There are two ways to become a donor:

- Living organ donation: a living person voluntarily donates an organ (such as a kidney) to someone in need
- Deceased organ donation: organs are taken from a recently deceased person and given to someone in need. This would happen if:
    - The person who died had already agreed to become an organ donor by signing up to be a donor through a provincial plan; often the person had a wallet card with this information on it
    - The decision was written in the Advance Care Plan
    - The person who is considered next of kin would be approached by the medical team to see if organ donation can take place

Different provinces and territories in Canada may have different protocols for organ donation. Speak to your primary healthcare provider for more information.

MISCELLANEOUS LEGAL MATTERS

Advance Care Plans are not the only things to consider when putting your affairs in order. There is no telling when it may be needed, but it is wise to have all financial and legal documents up to date. These documents are best kept in a safe place that is known to a loved one.

You may also wish to consider the following:

- Legal will: a will takes effect upon a person’s death and states how finances, property and personal items are to be divided to those the person has included in the will—seeking legal assistance in making a will is recommended
- Power of Attorney/Power of Personal Care/Substitute Decision Maker: these terms refer to a person or persons who will speak or act for you on your behalf in various situations, should you be unable to do so—seeking legal assistance is recommended in order that you understand the roles and that the document is properly completed

Some lawyers will come to your home to help with these documents to make this process easier for individuals and/or family members.

FREQUENTLY ASKED QUESTIONS BY THOSE LIVING WITH AMYLOIDOSIS

People living with cardiac amyloidosis often have questions about the same things. If you can’t find the answer to the questions you have, please contact your healthcare provider to discuss.

Can I Drive?

Whether or not you drive depends on how you are feeling and your overall health. Generally, people can drive as long as their heart condition is under control but many other factors may be involved in this decision.

If your healthcare provider feels your health affects your ability to drive safely, this must be reported to your provincial agency responsible for driving safety. There is a National Safety Code in Canada (Determining Driver Fitness in Canada) which guides healthcare providers on whether a person is medically fit to drive. This might mean restrictions need to be put on your driver’s licence or having your licence removed. Most important is your safety on the road and the safety of the public.

Can I Work?

Again, this depends on your overall health. Things to consider are how you are managing your amyloidosis and the type of work you do. For some people working might be helpful, but for others, it may not be. Every person and situation is different. Talk to your healthcare provider about what is right for you.

If your healthcare provider says you can work, you might be able to start as soon as your heart disease is under control. For others, you might have to gradually build up to doing all aspects of the work. Sometimes special arrangements with your employer might have to be made to accommodate you in the work setting.

What About Having Sex?

Some people worry about whether it is safe to have sex when they have a heart condition. Once your heart condition is under control, you should be able to have an active and safe sex life. Human touch and sexual relations are part of a healthy life.

Sex is a form of exercise. When you have sex it can take a lot of energy, both emotionally and physically.

Sex should be fun and feel good. Here are some suggestions:

- Wait at least 1 hour after eating before sex
- Do not drink alcohol before sex
- Choose a time when you are rested and relaxed
- Choose a comfortable place where it is not too hot or cold
- Stop and rest if you get short of breath or feel uncomfortable
- Don’t get upset if you are not able to perform as you expected
- If sex is too difficult, find other ways to express love and affection
- Talk to your partner about how you feel

Problems are possible. Your interest in sex might go down. You might get short of breath during sex. Both men and women may experience sexual dysfunction. Problems can be a side effect of a medication or a sign your heart condition is getting worse. Talk to your healthcare provider about any concerns. If you are prescribed a medication for erectile dysfunction, make sure your pharmacist reviews all your other medications because there may be drug interactions.

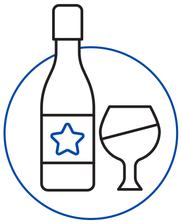
How Do I Stay On Track During Special Occasions?

Holidays and special events can often get people off of their usual routines.

Whether eating out or eating in, food is more likely to be high in salt—especially sauces and gravies. Also, people tend to eat and drink more on special occasions. Here are some tips:

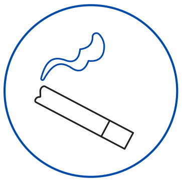
- Continue to make healthy choices
    - Choose food prepared with little or no salt
    - Where possible, choose fresh vegetables and fruit
- Plan big meals for midday
- Pay special attention to your snacking and portion size
- Monitor your fluid intake—both amount and type
    - Aim for 1.5 to 2 litres of fluid per day

A WORD ABOUT…



Drinking alcohol

Some alcohol is okay for a normal heart. However, sometimes even a small amount of alcohol can cause a heart condition to get worse. Alcohol can weaken your heart muscle and increase your blood pressure, creating more work for your heart. Ask your healthcare team if any amount of alcohol is okay for you.



Smoking

Smoking and using tobacco products damage your heart and lungs. Vaping and using e-cigarettes are also harmful to your health. For most people, quitting these habits is not easy. Your chances of quitting are much better if you ask for help. Ask your healthcare team for help to quit smoking or using other such products or ways to deal with second-hand smoke. Getting the best information from an expert is the best way to proceed.

Cannabis Products

Cannabis products (recreational or prescribed) are being used more and more to help those with chronic medical conditions, although there is no known benefit that is specific to amyloidosis. If you are using cannabis products, or are interested in learning more, it is best to discuss this with your healthcare team.

RESOURCES

The following resources are from trusted organizations and may be of help to you. A word of advice - if you plan to look online for more resources, always make sure it is from a credible source.

Call 911 if help is required emergently.

Suicide Crisis Line – call or text 988 if you or someone you know is thinking about suicide. Help is available 24 hours a day, 7 days per week. Support is bilingual, trauma-informed, culturally appropriate and available to anyone in Canada.

The Indigenous Hope for Wellness Helpline 1- 855-242-3310 (toll free). Help is available 24 hours a day, 7 days per week in multiple languages by phone or online chat.
https://www.hopeforwellness.ca

Get Help Canada – lists support by province
https://www.canada.ca/en/public-health/campaigns/get-help-here.html

The Canadian Amyloidosis Support Network
https://amyloidosiscanada.org

Transthyretin Amyloidosis Canada
https://madhattr.ca

Canadian Supports for Caregivers
https://canadiancaregiving.org

Caregiver Resources – Canadian Centre for Caregiving Excellence
https://canadiancaregiving.org/resources/caregiver-resources/#National

Anxiety Canada
www.anxietycanada.com

WORKSHEETS

The best way to stay on top of your condition is by monitoring how you feel and by taking "your numbers" – blood pressure, pulse and weight. The following worksheets can be used to daily track your findings.

Worksheets

Self-Monitoring Symptom Tracker Worksheet

Date	Symptom(s)	Duration: how long did symptoms last?	Action taken and result
Ex: April 14, 2025	Ex: Shortness of breath	Ex: 30 minutes – while exercising OR lasted all day	Ex: Continued exercise; resolved when exercise stopped OR contacted health care provider; medication adjusted

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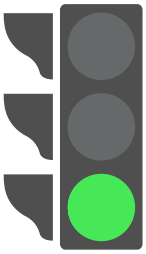
Refer to next worksheet entitled “Self-monitoring Symptom Tracker” for examples of important symptoms to monitor.

Please contact your healthcare provider, or present to your nearest emergency room if you are feeling unwell.

Self-Monitoring Symptom Tracker

Use this tool to help monitor your ongoing heart health and any changes to symptoms.

HEART FUNCTION ZONES



THE SAFE ZONE

Your symptoms are under control.

- ✔ no new or worsening shortness of breath
- ✔ no changes to your activity level
- ✔ no new swelling in legs, feet or ankles
- ✔ weight is stable. Wt ____
- ✔ no pain, tightness, pressure in chest

THE CAUTION ZONE

Your symptoms are beginning to change and should be reported.

- ▲ some shortness of breath with activity or when sleeping
- ▲ dry, hacking or productive cough
- ▲ swelling in legs, feet, ankles or abdomen
- ▲ weight gain of more than 2 kg (4 lb) in two days, or more than 2.5 kg (5 lb) in one week
- ▲ sometimes feel dizzy or lightheaded but goes away with rest
- ▲ chest pain, pressure or tightness that goes away with rest or prescribed medicine

Contact your healthcare provider as you may need a change to your medications.

THE DANGER ZONE

Your condition has changed. Action is needed.

- ⃠ shortness of breath now happens at rest, can't catch your breath
- ⃠ frequent dry, hacking, productive or blood-tinged cough
- ⃠ severe swelling of legs, feet, ankles or abdomen
- ⃠ weight gain has been severe and sudden
- ⃠ severe dizziness, lightheadedness, fainting or confusion
- ⃠ chest pain, pressure or tightness, racing heart that does not go away with rest or prescribed medicine
- ⃠ cannot sleep flat (unable to lie flat); need extra pillows or sit up in chair to sleep

Warning Alert!

You need to be checked out NOW.
Call your healthcare provider, call 911, proceed to Emergency.

Daily Weight Tracker

Name: ____________________

- Record your weight daily and compare it to the previous day's weight.
- It is best to weigh yourself every morning at the same time.

Month ____________________

Sunday	Monday	Tuesday	Wednesday	Thursday	Friday	Saturday

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If you notice a SUDDEN GAIN of more than 2 kg (4 pounds) over 1 to 2 days, or 2.5 kg (5 pounds) in a single week, please contact your health care provider.

Excess fluid buildup in your body makes your heart work harder. Checking your weight every day lets you know if your body is retaining fluid. When you report weight gain early to your health care provider, they can help prevent this from getting worse. This may help prevent a trip to the emergency room or hospital stay.

Medication Tracker

Name: ____________________ Doctor's name: ____________________

Prescribed Medication:

	Medication Name(s)	Dosage	Frequency	Purpose / Description	Date: Medication Adjustments
1	*ex. Lasix*	*ex. 40 mg*	*ex. Daily (morning)*	*ex. Water pill*	*ex. Increased to 60 mg Feb 14/25* *ex. Discontinued Feb 14/25*
2					
3					
4					
5					
6					
7					
8					
9					
10					
11					
12					
13					
14					

Non-Prescription Medications including vitamins and supplements:

Daily Tracker

Name: ______________________ Month: ______________________

Date	Blood Pressure	Heart Rate	Weight

Exercise & Activity Tracker

Name: ______________________ Month: ______________________

Use the following tracker to record exercise and physical activity.

Date	Time & Duration	Activity	Symptoms
ex. Jan 1, 2025	*ex. 8:30 am / 30 mins*	*ex. Walking, gardening, etc*	*ex. No symptoms*

WHAT TO DO WITH Heart Failure Medications IF I'M SICK

Adapted from the 2020 Canadian
Cardiovascular Society
Heart Failure and
Diabetes Canada Guidelines

RxFILES

Name: ______________________ **Date:** ______________________

- When you are sick, it is easy to become dehydrated from throwing up, diarrhea, and/or a fever.
- If you become dehydrated, your body may be stressed. This can make certain medications cause problems.
- This means that **some** medications should be PAUSED when you are sick to prevent side effects.
- These medications can then be STARTED AGAIN once you have recovered from being sick.

MY PLAN

If I have been throwing up, having diarrhea, or a fever and I am worried that I am dehydrated because I cannot keep "anything down" for more than 24 hours, I will PAUSE (temporarily stop) the following medicine(s):

Type of Medication	My Medication	
diuretic (water pill; e.g. furosemide **LASIX**, metolazone **ZAROXOLYN**)	☐	
ACE inhibitor (e.g. ramipril **ALTACE**)	☐	
angiotensin receptor blocker (e.g. valsartan **DIOVAN**)		
sacubitril-valsartan (**ENTRESTO**)		
spironolactone (**ALDACTONE**) or eplerenone (**INSPRA**)	☐	
SGLT2 inhibitor (e.g. dapagliflozin **FORXIGA**, empagliflozin **JARDIANCE**) **Go to the emergency department if you have abdominal pain, severe vomiting, or severe drowsiness.**	☐	
others (such as metformin **GLUCOPHAGE**, glyburide **DIABETA**, gliclazide **DIAMICRON**)	☐	

For medications not included in this list, continue taking them as prescribed or consult your cardiologist, family physician, pharmacist, or heart function clinic.

I will START these medications again at my usual dose when I am feeling well and my body has recovered from the illness.

For cough and cold products, do not take any products that contain:

- anti-inflammatory drugs such as ibuprofen **ADVIL**, **COMBOGESIC**, **MOTRIN** or naproxen **ALEVE**
- acetylsalicylic acid **ASPIRIN** for pain or fever; daily low-dose for cardiovascular protection is okay if prescribed
- decongestant tablets or sprays containing pseudoephedrine or phenylephrine

Instead, you can use:

- acetaminophen **TYLENOL** for pain or fever
- saline (salt water) nose spray **SALINEX** or rinse for congestion

SIGNS OF DEHYDRATION

unusually weak or tired

confused or
trouble focusing

thirsty, dry mouth

cool, clammy skin

less peeing

new or worsening dizziness
or light-headedness when
standing or sitting up

WHEN YOU ARE SICK IT IS OKAY TO PAUSE THESE MEDICATIONS FOR A FEW DAYS.

REMEMBER TO:

HYDRATE

try to keep total fluids to around 2 litres per day, limiting caffeinated beverages and replacing fluid loss from throwing up or diarrhea

WATCH SODIUM INTAKE

canned soup & packaged foods are convenient but can cause your body to hold onto extra fluid

KEEP TRACK

continue weighing yourself daily and if you have a machine at home, check your blood pressure and heart rate twice a day, especially if you feel lightheaded

CONSULT

your provider if you have questions, if your weight goes ↑or↓ by more than 1.5 kgs (≈ 3lbs) over 2 days, if your blood pressure is unusually low for you, or if you need to PAUSE your medications for more than 2 days

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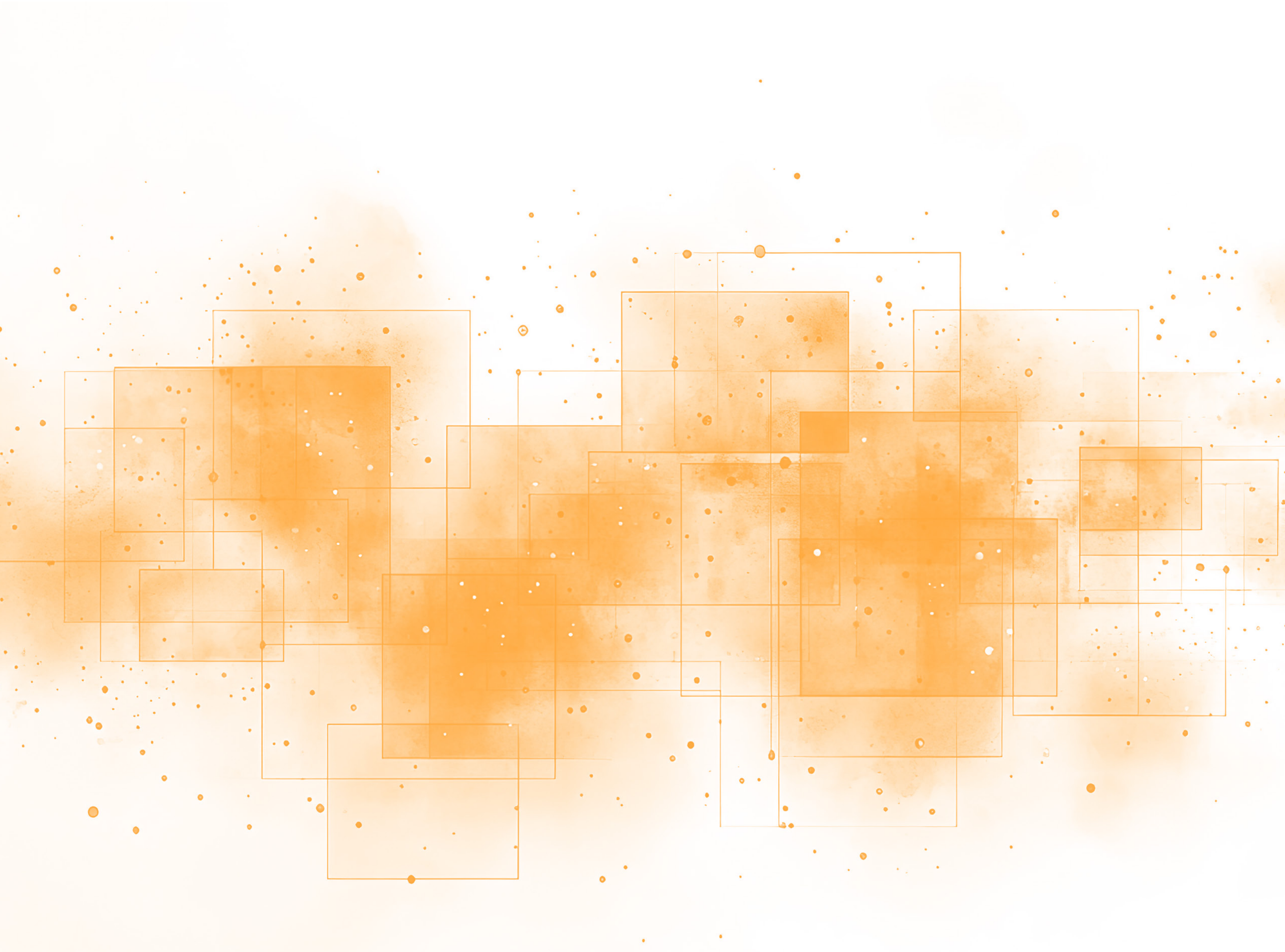

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