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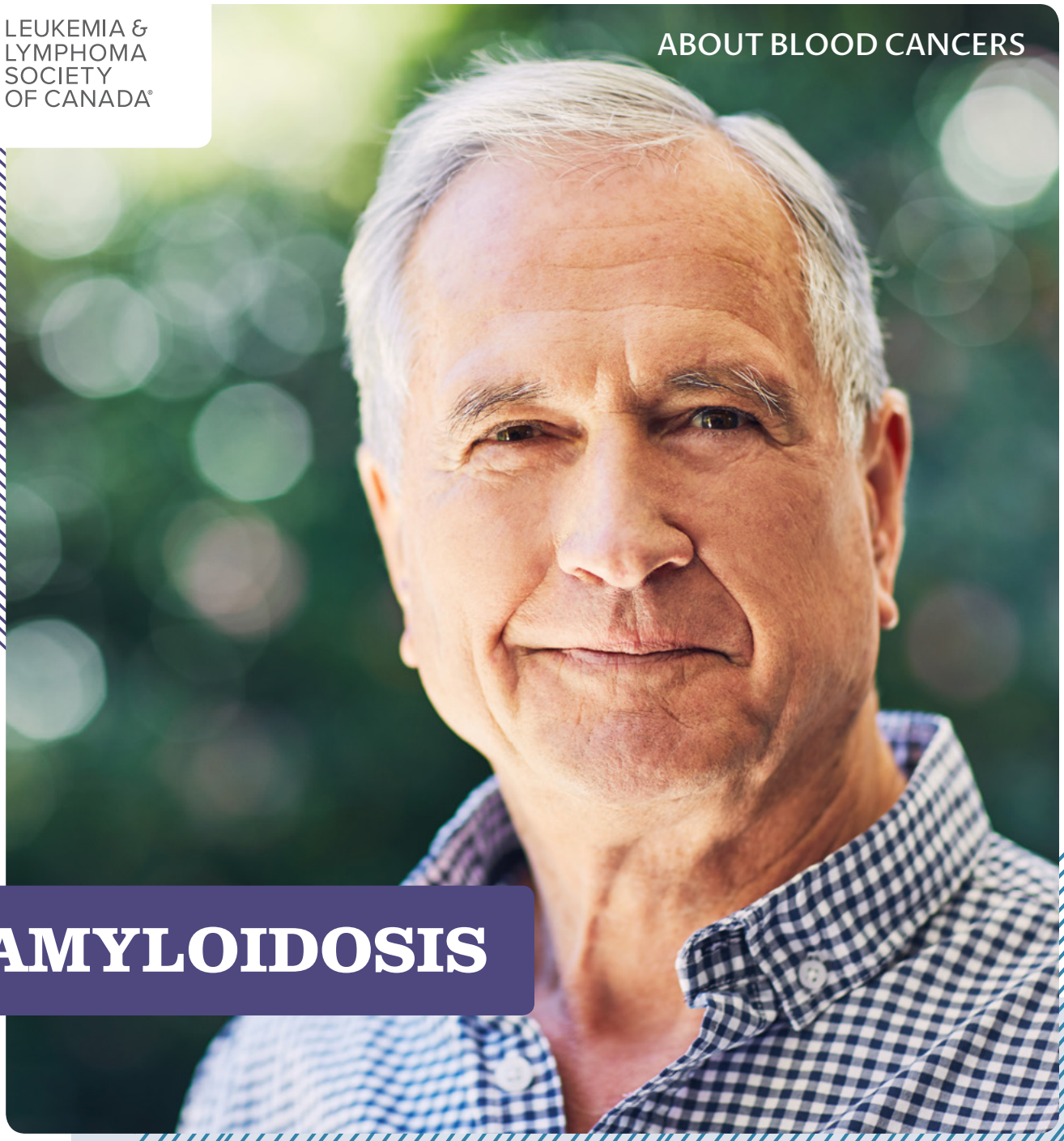

AMYLOIDOSIS

WHAT YOU NEED TO KNOW

You or your loved one has been diagnosed with amyloidosis. What does it mean and how will it affect you?

This fact sheet will help you:

- Learn about amyloidosis and how it is diagnosed
- Get an overview of treatment options
- Understand what happens next

What is amyloidosis?

Amyloidosis is a rare disease where an abnormal protein called amyloid builds up in your organs, such as your heart, liver, and kidneys. This abnormal protein is produced in the bone marrow, where blood cells are formed. It can cause your organs to not work properly.

About amyloidosis	• There are many different types of amyloidosis. • Most types are not associated with a blood cancer. • Amyloid light-chain amyloidosis is linked with a blood cancer called myeloma. • Amyloidosis can progress quickly.

Signs and symptoms	Most people with amyloidosis have no obvious signs or symptoms until the disease is more advanced. Blood and urine tests, tissue biopsies, and X-rays can help your doctor diagnose it. The signs and symptoms, which can be similar to less serious or more common diseases, depend on which organ is affected. You may experience:
	• Enlarged tongue
	  - Caused by protein deposits
	• Fatigue and/or weight loss
	  - When your red blood cell count is low (anemia)
	• Heart or kidney failure
	  - Caused by a build-up of amyloid (abnormal protein)
	• Skin nodules (small growths), nail changes, hoarse voice, and dark discoloration around the eyes
	• Joint enlargement
	  - When amyloid builds up in your connective tissues (between bones)

Amyloidosis is a rare disease that can be present on its own or with myeloma, a type of blood cancer.

Because amyloidosis can lead to organ damage, it is important to diagnose it quickly.

After your diagnosis

With your diagnosis, your doctor can determine the right treatment for you. Your test results help your doctor predict how amyloidosis will likely progress and how you may respond to treatment. A precise diagnosis is important, as the treatment depends on your specific type.

Name of test	Description
Medical history and physical exam	The doctor reviews past illnesses, injuries, and symptoms. They examine your lungs, heart, and other organs.
Blood and urine tests	Blood and urine tests look for a certain protein, called M (monoclonal) protein, to determine how present the disease is in your body.
Bone marrow aspiration and biopsy	These two tests look at bone marrow cells for anything unusual with your chromosomes. They are usually done at the same time.
Skeletal survey	This series of X-rays evaluates the major bones of the body.
Congo-red staining	This test removes a small piece of tissue from the abdominal fat pad. The tissue is then stained and reviewed in the lab to help confirm a diagnosis.

Amyloidosis treatment

There is no cure for amyloidosis. Your treatment will focus on managing the symptoms and complications rather than curing the disease.

Types of treatment

For the main type of amyloidosis, known as AL amyloidosis, the treatment is similar to the treatment for myeloma. It can often improve your condition and extend your life.

Chemotherapy and stem cell transplantation	Use high doses of chemotherapy drugs (chemicals), followed by a transplant of your own stem cells to slow the growth of your disease.
Solid organ transplant	T ransfers a healthy person's (donor) organ to your body to replace a damaged organ.
Clinical trial	You may be eligible for a clinical trial of a new treatment. Your doctor can advise you on this.
Managing the symptoms	Managing the symptoms of amyloidosis is important. Your doctor may recommend: • Pain medication • Medication (a diuretic) to reduce fluid retention • A low-salt diet • Blood-thinning medication • Medication to control your heart rate

Factors that affect treatment

Discuss your treatment options with your doctor to make sure you understand the benefits and risks of each approach. Your treatment plan is based on:

- Your age and overall health status
- Your prognosis (the likely outcome of the disease)

Treatment side effects

When you begin your treatment for amyloidosis, you may experience mild to severe side effects, depending on your age, your overall health, and your treatment plan. Most side effects disappear once your treatment ends. New drugs and therapies can help control most side effects. Speak to your doctor if you are having side effects.

Common side effects	You may experience side effects such as: • Nausea, diarrhea, vomiting, reflux, bloating, and constipation from your chemotherapy treatments • Low blood cell counts, mouth sores, extreme fatigue, fever, cough, and hair loss from your chemotherapy treatments • Neuropathy, which is nerve damage from treatment that can make your fingers and toes feel numb or tingle • Suppressed immune system from a kidney or heart transplant
Long-term or late effects of treatment	Medical follow-up is important after treatment for amyloidosis to monitor your involved organs and immunoglobulins produced by abnormal plasma cells. You may need blood tests, bone marrow tests, or molecular tests to determine if you need further treatment. Your medical team should provide you with a care plan listing the frequency of follow-up visits and the tests you will have at those visits. • **Long-term side effects** are common and can last for months or years after treatment ends. Examples include chronic fatigue and problems concentrating (known as chemo brain.) • **Late effects** are medical problems that do not show up until years after treatment ends. See your doctor to get follow-up care for possible early detection of a secondary cancer.

Living with amyloidosis can be hard. Seek medical help if you feel "down" or "blue" or don't want to do anything and your mood does not improve over time. These could be signs of depression, an illness that should be treated even when you're undergoing treatment for amyloidosis. Treatment for depression has important benefits for people living with cancer.

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