



Understanding indolent non-Hodgkin lymphoma (iNHL)

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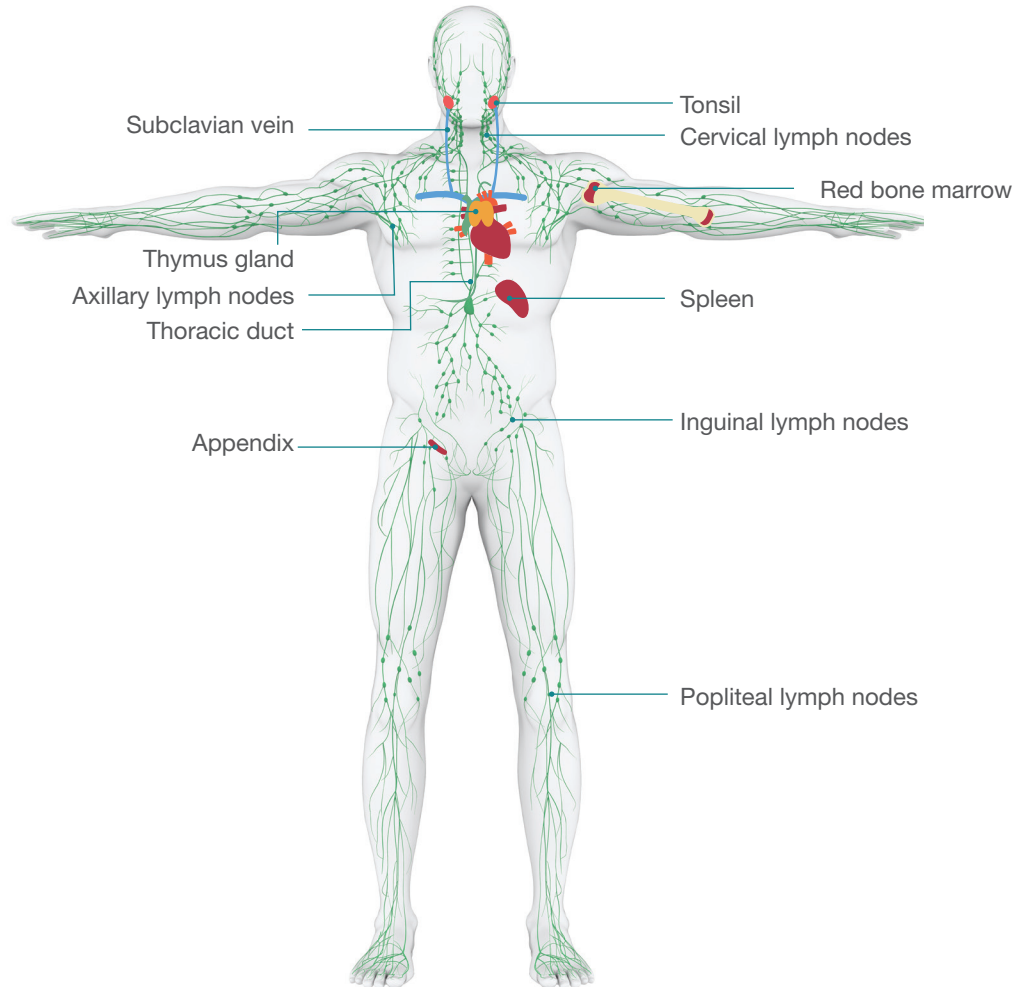
Understanding your diagnosis of iNHL

This guide will help you and your loved ones understand your diagnosis of iNHL. In order to manage your diagnosis, basic information will be covered regarding treatment options and lifestyle modifications. The topics in this booklet will assist you in asking the right questions in order to have an informed conversation with your healthcare providers and counsellors.

This resource does not take the place of discussions with your physician and healthcare team. After reading this booklet, you should ask any questions that you may have to a member of your healthcare team.

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The human immune system organs



Understanding iNHL

What is lymphoma?

The lymphatic system is part of your body's immune system which normally helps fight infections and other diseases. Lymphoma is a cancer of the lymphatic system. The cancer starts when cells begin to grow out of control in white blood cells (called lymphocytes). Lymphomas can start anywhere in the body where lymph tissue is found.

Non-Hodgkin lymphoma is also known as non-Hodgkin's lymphoma, NHL, or sometimes just lymphoma.

What is iNHL?

iNHL is a classification of lymphoma that grows and spreads slowly. All non-Hodgkin lymphomas can spread to other parts of the lymph system, and eventually to other parts of the body such as the liver, brain, or bone marrow, if not treated.

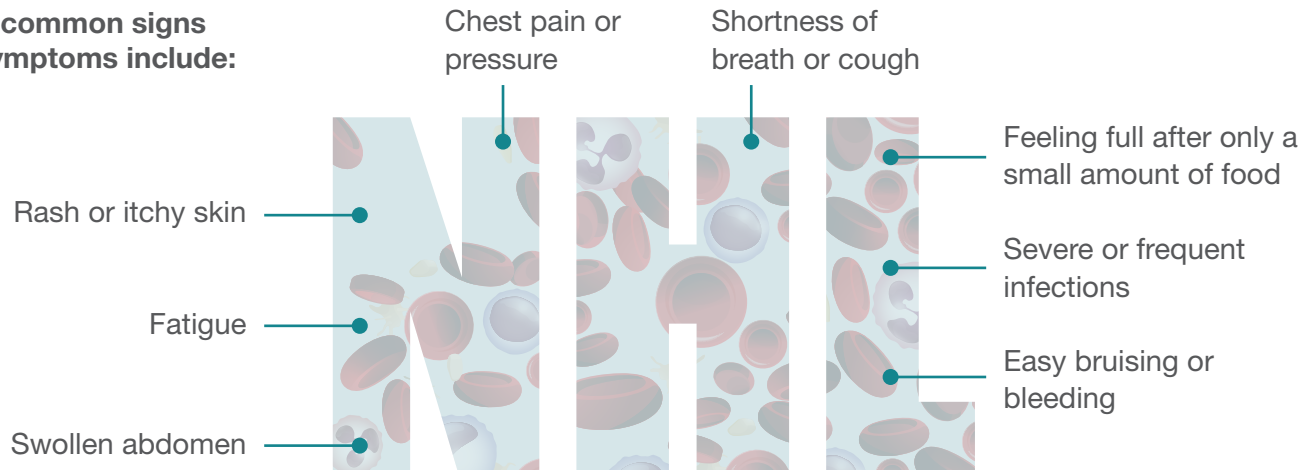
Signs and symptoms of NHL

What are the common signs and symptoms of NHL?

Often, NHL is first detected during a routine medical exam and you may not have noticed any symptoms.

The most common symptom of NHL is swollen, or enlarged, lymph nodes in the neck, armpit or groin. The swollen lymph nodes are usually painless, but they can eventually put pressure on tissues or organs around them and cause discomfort or pain.

Some common signs and symptoms include:



Some symptoms of NHL are more generalized, which means that they affect the whole body. Some people with NHL may have what are known as B symptoms:

- Fever without an infection
- Drenching night sweats
- Weight loss

What are the causes and risk factors for NHL?

The cause of NHL, including iNHL, is unknown.

There are several known risk factors for NHL, including a weakened immune system, certain infections, previous cancer treatments and exposure to lindane. The risk of developing iNHL increases as you get older and is more common in people over age 60.

Questions to ask your healthcare provider about iNHL

- What is the status of my iNHL?
- How does the disease progress?
- How long does it take for the disease to progress?
- What is the outlook (prognosis) for my iNHL?

How does your doctor know that you have iNHL?

Tissue Biopsy

Your doctor may find swollen or enlarged lymph nodes during a routine examination. Swollen lymph nodes usually don't require medical care and will return to normal within a short period of time.

If your lymph nodes remain swollen or grow even larger, your doctor may order a lymph node biopsy. A tissue biopsy is removal of part or all of the tissue which will be sent for further examination.

In many cases, lymph node biopsy will be performed using local anesthesia and does not require hospitalization. Your doctor will advise you of which biopsy technique is most appropriate.

You may experience some pain and swelling around the biopsy site, bleeding or numbness after the biopsy and in rare cases you may develop an infection that can be treated with antibiotics.

What other tests are done?



Blood tests

Some or all of the following tests may be performed on blood samples collected by your doctor. Your medical team will decide which tests are needed.

- **Complete blood count (CBC)**

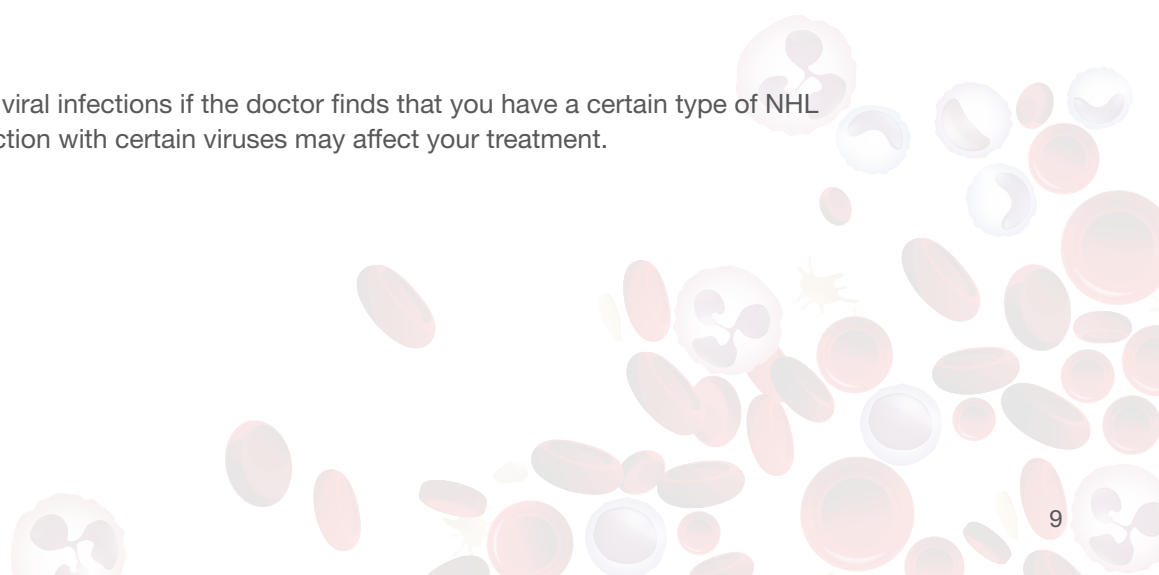
A CBC measures the number and quality of all the cells in your blood.

- **Blood chemistry tests**

Blood chemistry tests measure certain chemicals in the blood. They show how well certain organs are functioning and can help find abnormalities.

- **Other blood tests**

You may be tested for certain chronic viral infections if the doctor finds that you have a certain type of NHL or if certain treatments are given. Infection with certain viruses may affect your treatment.





Imaging tests

Blood tests and tissue biopsies are often enough to confirm that you have a form of NHL. Because NHL can affect many different lymph nodes and organs in the body, your doctor will schedule you for several imaging procedures that will determine which organs in your body are affected.

- **Chest x-ray**

An x-ray uses small doses of radiation to make an image of the body's structures on film.

- **Computed tomography (CT) scan**

A CT scan uses special x-ray equipment to make more detailed images of organs, tissues, bones and blood vessels inside the body. The pictures of the enlarged lymph nodes and organs in different parts of the body allow the doctor to plan treatment.

- **Magnetic resonance imaging (MRI)**

MRI uses powerful magnetic forces and low-frequency radio waves to make more detailed images of the organs, tissues, bones and blood vessels inside the body.

- **Ultrasound**

Ultrasound uses high-frequency sound waves to make images of structures in the body. It is used to check if the liver, spleen or testicles are swollen and for signs of NHL in these organs.

- **Bone scan**

A bone scan uses bone-seeking radioactive materials (called radiopharmaceuticals) and a computer to create a picture of the bones.

- **Positron emission tomography (PET) scan**

A PET scan uses radioactive materials to look for changes in the activity of body tissues. A computer analyzes the radioactive patterns and makes 3-D colour images of the area being scanned.

How does the type of NHL diagnosis affect my treatment?

The individual treatment plan that your healthcare team will create for you is based on your diagnosis, prognostic factors and if you have already been treated for NHL. Your age, overall health and specific information about your type of NHL, such as the type, grade and stage are also taken into account in your treatment plan.

NHL Types

There are more than 30 different types of NHL based on which cells are involved. The major subdivisions of NHL are based on the type of immune cells affected.

Low-grade or indolent NHL

Because there are few symptoms when the disease first appears, most patients do not seek treatment until symptoms become noticeable. By this time, the disease may have spread throughout the body and may affect a number of different organs.

Stages of iNHL

When indolent lymphoma is located only in 1 or 2 areas adjacent to the affected lymph node, it is called localized disease and is considered to be stage I or II.

Treatment timing

- **Watchful waiting or active surveillance:** Treatment only starts when symptoms develop or the disease begins to change. This period of time, before therapy starts, is called watchful waiting or active surveillance.
- **Localized disease:** For people with localized disease (stage I or II), radiation therapy is often used. However, most patients with indolent NHL have stage III or IV disease at the time of diagnosis.
- **Stage III or IV:** This means that the cancer has spread and involves other tissues and organs. There are many effective treatments for these stages of indolent NHL; however, it may come back months or years after treatment has finished and require more treatment.
- **Progressive/refractory disease:** If the cancer spreads or grows while treatment is in progress, this is called progressive or refractory NHL.
- **Recurrent/relapsed disease:** If the lymphoma comes back after treatment, it may be in the area where it first started or in another part of the body. Recurrence may occur soon after the first treatment or years later. This is also called relapsed NHL.

Types of treatment

There are 4 main treatments for NHL:

- **Chemotherapy:** Usually a combination of chemotherapy drugs is given, but in some cases a single chemotherapy drug may be used.
- **Immunotherapy:** Designed to boost the body's natural defenses to fight cancer, immunotherapy may be used on its own or in combination with chemotherapy to treat some types of NHL.

- **Radiation therapy:** External beam radiation may be given to specific areas of the body to shrink a tumour or swollen lymph node and to reduce the pain that it is causing.
- **Targeted therapy:** Drugs that block certain functions within the lymphoma cell can be used alone to treat some advanced stage, B-cell-type iNHL. This type of treatment, which uses monoclonal antibodies, is most often given in combination with chemotherapy. Some targeted therapy drugs are used to carry radiation directly to the lymphoma cells. This treatment is called radioimmunotherapy.

Occasionally, a doctor may consider surgery or bone marrow (stem cell) transplantation. However, this is considered an aggressive treatment and is generally used to treat progressive, relapsed or refractory iNHL if other treatments don't work.

Some examples of questions to ask your healthcare provider about treatment options

- What is the status of my disease?
- What are my treatment options?
- Why are you recommending this option?
- What are the possible risks and benefits?
- What side effects could I have?
- Will I need to stay in the hospital?
- How will we know if the treatment is working?
- How will this affect my day-to-day life?

Follow-up care

Follow-up care after treatment is an important part of cancer care. Follow-up for iNHL is often provided by the cancer specialists (oncologists or hematologists) and your family doctor. Your healthcare team will work with you to determine your specific needs for follow-up care.

Schedule for follow-up visits

Follow-up visits for iNHL are usually scheduled for many years after treatment even if there are no signs of the disease. The appointments will eventually become less frequent, but you will need to see your doctor regularly for a long period of time.

Some examples of questions to ask your healthcare provider about side effects

- What are the possible side effects of my treatment?
- Can side effects be prevented or managed?
- When should I call you if I am having side effects?
- Who can I contact if I can't reach you?



Be involved in your treatment plan

Being diagnosed with iNHL may be overwhelming and you may feel unsure of what to do next or how to proceed with your treatment plan. It is important to remember that along with your team of healthcare professionals, you are an influential member of the treatment process.

**When it comes to your health, your role is important.
Remember to be involved in your course of treatment.**

Your healthcare team

After your diagnosis of iNHL, you will meet with your healthcare team. Your team will include a number of healthcare professionals, who will help you along the course of your treatment. Your team may include an oncologist, hematologist, pharmacist, nurse, social worker and a dietitian. Each member of the team will work to provide you with resources and support during your treatment. You will also receive supportive care coordinated by the members of your healthcare team.

Therapy programs

Complementary therapy programs are offered at many cancer centers and local hospitals, which have yoga, acupuncture and meditation programs.

Accepting help

You may be hesitant to accept help, but your family members and close friends really want to support you and provide assistance. You can remind them of the following:

- They should act as usual when they are with you.
- They should listen to your complaints without immediately proposing a solution.
- They must not forget that you are still the person that they have always known.

You can also provide a more specific answer by listing your immediate and future needs, which might include the following:

- Taking care of your children or pets
- Grocery shopping or preparing meals
- Transporting you to and from your medical appointments

When a family member becomes ill, the usual roles and responsibilities of each member of the family can change.

- You may need your children to become more involved in taking care of daily chores.
- Your partner may have to manage the bills, run errands and do more of the tasks to maintain your home and property.
- Your partner may feel the need to find employment.



Be aware of your feelings

Since you learned about your diagnosis, you may have experienced a variety of emotions. However, it is important to remember that if these feelings disrupt your daily routine, it may be helpful to seek professional advice.

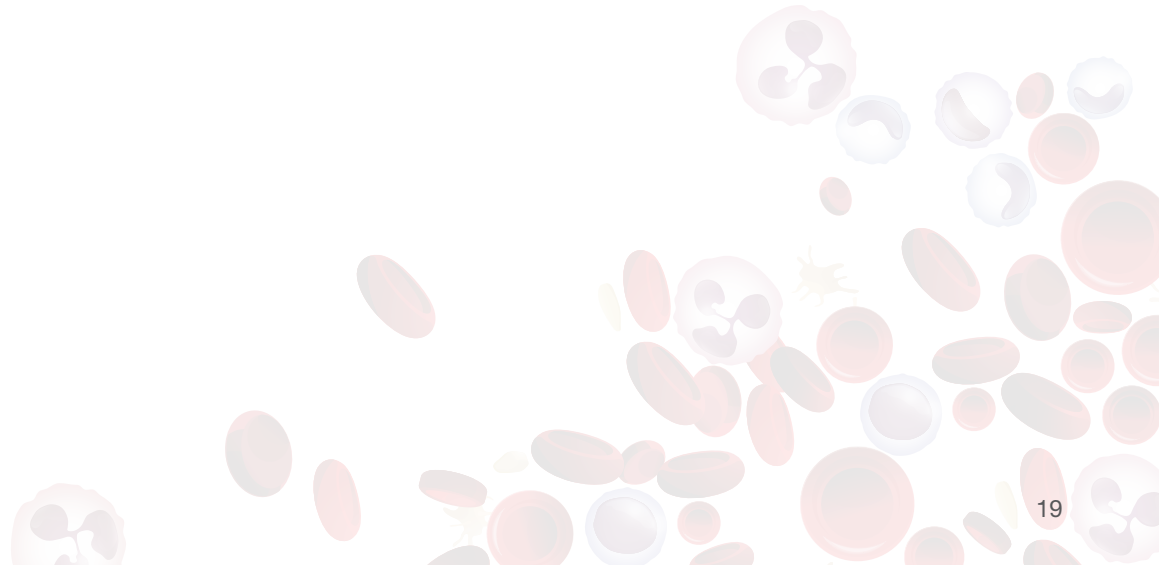
Speak to your healthcare professional about how you are feeling.

Share your feelings

Talking about your feelings can help you to accept them. Start by confiding in a close friend or family member. If this is not possible, you can seek help from professionals who can advise you on how to deal with the situation.

Join a support group

Although you may sometimes feel alone, remember that there are many others who are experiencing the same difficulties. Join a support group. This could be a very valuable experience which might teach you how to manage your feelings. Some groups meet in person and others exchange information via the Internet. Some people speak openly and others prefer to listen. You will not be forced to do anything that makes you feel uncomfortable. Your healthcare team will certainly be able to guide you to a support group close to you.



Managing your finances

Take time off from work

Depending which treatment you will receive, you may have to take some time away from work. To determine how much sick leave you should ask for, meet with someone from your employer's human resources department or someone from your insurance company.

Ask for help managing your finances

During the different stages of your treatment, you may not have enough time or energy to manage your finances. Think of asking a family member or a close friend to take care of your bills, insurance forms and other financial aspects to help you keep things organized. Knowing that your finances are being taken care of will eliminate one worry during this difficult time.

How to support someone living with iNHL

Here are a few things you can do to help take care of a loved one living with iNHL:

- Listen. One of the most valuable things you can do as a caregiver is listen to your loved one's needs and concerns.
- Stay organized. Helping your loved one schedule their doctor's visits and preparing a list of questions to ask during the appointment can all be useful ways of staying organized throughout this treatment journey.
- Help them with their daily needs. Whether that be preparing meals or running errands, taking on these simple tasks can provide great relief to your loved one.
- Educate yourself. Learning more about iNHL and the treatment options available help you and your loved one understand the information available and clarify what you can do to help.

Take care of yourself

- Give yourself time to understand and work through your emotions. It may be helpful to share your feelings with other loved ones, join a support group, or speak with a mental health professional.
- Make time for yourself. Find nice things to do for yourself each day; even just a few minutes can help.
- Seek help from others. Reach out to your support group and find things they can do or arrange for you, such as appointments or errands.
- Find a quiet time for reflection each day. Remember the things you need to maintain a healthy mind, body, and spirit.

Notes

To assist you in keeping your healthcare team information in one place, write in their contact information in the area provided below.

Use this page to write down the name and contact numbers of the members of your healthcare team.

Name _____
Title _____
Phone _____
Address _____

Email _____

Name _____
Title _____
Phone _____
Address _____

Email _____

Name _____
Title _____
Phone _____
Address _____

Email _____

Other important numbers

Nurse _____
Religious or spiritual advisor _____
Pharmacy _____
Hospital _____
Emergency contact _____

Glossary

Biopsy: The removal of cells or tissues for examination by a pathologist, a doctor specialised in the analysis of blood, body fluids and tissues. The pathologist can examine the samples with a microscope or perform tests on them. There are many types of biopsy procedures.

Clinical trial: A type of research that assesses health tests or treatments.

Complete blood count (CBC): Test used to determine the number of red blood cells, white blood cells and platelets in a blood sample.

Hematologist: A doctor who has special training in diagnosing and treating blood disorders.

Indolent non-Hodgkin lymphoma (iNHL): Cancer characterized by low-grade tumours in the lymphatic system that grow slowly, with patients often being completely without symptoms.

Lymph node: A small bean-shaped structure that is part of the body's immune system. Lymph nodes filter substances that travel through the lymphatic fluid, and they contain lymphocytes (white blood cells) that help the body fight infection and disease. There are hundreds of lymph nodes found throughout the body. They are connected to one another by lymph vessels.

Lymphatic system: The lymphatic system is made up of a network of lymph vessels, lymph nodes and the lymphatic organs. Lymph vessels carry lymph fluid, which contains lymphocytes and other white blood cells, antibodies and nutrients. Lymph nodes sit along the lymph vessels and filter lymph fluid. The lymphatic organs include the spleen, thymus, adenoids, tonsils and bone marrow.

Lymphoma: Lymphoma is cancer that begins in infection-fighting cells of the immune system, called lymphocytes.

Non-Hodgkin lymphoma (NHL): A cancer that starts in lymphocytes. Lymphocytes are cells of the lymphatic system.

Oncologist: A doctor who has special training in diagnosing and treating cancer. Some oncologists specialize in a particular type of cancer treatment.

Platelets: A type of blood cell that helps control bleeding.

Progressive disease: If the cancer grows larger or spreads while the patient is being treated for the original lymphoma, it is called progressive disease. This is also called **refractory** disease.

Refractory disease: Patients who still have lymphoma cells in their bone marrow after NHL treatment have a refractory form of lymphoma.

Relapsed disease: When aggressive NHL has progressed after initial treatment, it is called **relapsed** or **recurrent** disease.

Stem cell: A cell from which blood cells and other cells develop.

Stem cell transplant: Operation to replace the immature hematopoietic cells killed by chemotherapy, radiation therapy or illness. Stem cell transplants are performed after treatment to promote re-establishment of the bone marrow and the production of healthy blood cells.



Resources

National Comprehensive Cancer Network

A not-for-profit alliance of 28 leading cancer centers devoted to patient care, research, and education.

National Comprehensive Cancer Network

<http://NCCN.org/patients>

Health Canada's Clinical Trials Database

Health Canada's database about clinical trials provides Canadians with a list of precise information about ongoing clinical trials.

Health Canada's Clinical Trials Database

<https://www.canada.ca/en/health-canada/services/drugs-health-products/drug-products/health-canada-clinical-trials-database.html>

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