



After Treatment for Waldenstrom Macroglobulinemia

Living as a Cancer Survivor

For many people, cancer treatment often raises questions about next steps as a survivor.

- [What Happens After Treatment for Waldenstrom Macroglobulinemia?](#)
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Cancer Concerns After Treatment

Treatment may remove or destroy the cancer, but it is very common to have questions about cancer coming back or treatment no longer working.

- [If Treatment for Waldenstrom Macroglobulinemia Stops Working](#)

What Happens After Treatment for Waldenstrom Macroglobulinemia?

Current [treatments](#) for Waldenstrom macroglobulinemia (WM) are not likely to result in a cure. Most people with WM are treated for some time, followed by a break, and then treated again when the disease comes back. Learning to live with cancer that does not go away can be difficult and very stressful. [Managing Cancer as a Chronic Illness](#) has more about this.

Follow-up care

Even during treatment breaks, your doctors will still want to watch you closely. It is very important to go to all of your follow-up appointments. During these visits, your doctors will ask questions about any problems you are having, and may examine you and get lab tests or imaging tests (such as CT scans) to look for signs of cancer or treatment side effects.

Almost any cancer treatment can have [side effects](#). Some may last for only a short time, but others can last longer, possibly even for the rest of your life. Tell your cancer care team about any changes or problems you notice and about any concerns you have.

Follow-up visits usually include a careful physical exam. The doctor will also check how you are feeling. Be sure to report any new or ongoing symptoms. Your blood cell counts, IgM, and beta-2 microglobulin levels will be checked. Blood chemistry tests and other tests may also be done to see whether the abnormal IgM is damaging the kidneys, liver, or other organs. The choice of tests depends on your symptoms and what treatment (if any) you have received.

It is very important to keep your health insurance during this time. Tests and doctor visits cost a lot, and even though no one wants to think of their cancer coming back or getting worse, this could happen.

Should your cancer come back, [Coping with Cancer Recurrence](#) can give you information on how to manage and cope with this phase of your treatment.

Seeing a new doctor

At some point after your cancer [diagnosis](#) and [treatment](#), you may find yourself seeing a new doctor who does not know your medical history. It is important that you be able to give your new doctor the details of your diagnosis and treatment. Gathering these details soon after treatment may be easier than trying to get them at some point in the future. Make sure you have this information handy (and always keep copies for yourself):

- A copy of your pathology report(s) from any biopsies or surgeries
- Copies of imaging tests (CT or MRI scans, etc.), which can usually be stored digitally (on a DVD, etc.)
- If you had surgery, a copy of your operative report(s)
- If you stayed in the hospital, a copy of the discharge summary that the doctor wrote when you were sent home
- If you had [radiation therapy](#), a copy of the treatment summary

- If you had [chemotherapy](#), [targeted therapy](#), or [immunotherapy](#), a list of the drugs, drug doses, and when you took them
- The names and contact information of the doctors who treated your WM
- [References](#)

[See all references for Waldenstrom Macroglobulinemia](#)

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Lifestyle Changes With Waldenstrom Macroglobulinemia

You can't change the fact that you have had cancer. What you can change is how you live the rest of your life – making choices to help you stay healthy and feel as well as you can. This can be a time to look at your life in new ways. Maybe you are thinking about how to improve your health over the long term. Some people even start during cancer treatment.

Making healthier choices

For many people, a diagnosis of cancer helps them focus on their health in ways they may not have thought much about in the past. Are there things you could do that might make you healthier? Maybe you could try [to eat better or get more exercise](#). Maybe you could cut down on [alcohol](#), or [give up tobacco](#). Even things like keeping your stress level under control may help. Now is a good time to think about making changes that can have positive effects for the rest of your life. You will feel better and you will also be healthier.

You can start by working on those things that worry you most. Get help with those that are harder for you. For instance, if you are thinking about [quitting smoking](#) and need help, call the American Cancer Society at 1-800-227-2345 for information and support.

Eating better

[Eating right](#) can be hard for anyone, but it can get even tougher during and after cancer treatment. Treatment may change your sense of taste. Nausea can be a problem. You may not feel like eating and lose weight when you don't want to. Or you may have gained weight that you can't seem to lose. All of these things can be very frustrating.

If treatment causes weight changes or eating or taste problems, do the best you can and keep in mind that these problems usually get better over time. You may find it helps to eat small portions every 2 to 3 hours until you feel better. You might also want to ask your cancer team about seeing a dietitian, an expert in nutrition who can give you ideas on how to deal with these treatment side effects.

One of the best things you can do after cancer treatment is practice healthy eating habits. You may be surprised at the long-term benefits of some simple changes, like increasing the variety of healthy foods you eat. Getting to and staying at a healthy weight, eating a healthy diet, and limiting your alcohol can lower your risk for a number of types of cancer, as well as having many other health benefits.

To learn more, see our document [Nutrition and Physical Activity During and After Cancer Treatment: Frequently Asked Questions](#).

Rest, fatigue, and exercise

Extreme tiredness, called [fatigue](#), is very common in people treated for cancer. This is not a normal tiredness, but a bone-weary exhaustion that often doesn't get better with rest. For some people, fatigue lasts a long time after treatment, and can make it hard for them to exercise and do other things they want to do. But exercise can help reduce fatigue. Studies have shown that patients who follow an exercise program tailored to their personal needs feel better physically and emotionally and can cope better, too.

If you were sick and not very active during treatment, it's normal for your fitness, endurance, and muscle strength to decline. Any plan for physical activity should fit your own situation. A person who has never exercised will not be able to take on the same amount of exercise as someone who plays tennis twice a week. If you haven't been active in a few years, you will have to start slowly – maybe just by taking short walks.

Talk with your health care team before starting anything. Get their opinion about your exercise plans. Then, try to find an exercise buddy so you're not doing it alone. Having family or friends involved when starting a new activity program can give you that extra boost of support to keep you going when the push just isn't there.

If you are very tired, you will need to learn to balance activity with rest. It's OK to rest

when you need to. Sometimes it's really hard for people to allow themselves to rest when they are used to working all day or taking care of a household, but this is not the time to push yourself too hard. Listen to your body and rest when you need to. (For more information on dealing with fatigue, see [Cancer-related Fatigue](#).)

Keep in mind exercise can improve your physical and emotional health.

- It improves your cardiovascular (heart and circulation) fitness.
- Along with a good diet, it will help you get to and stay at a healthy weight.
- It makes your muscles stronger.
- It reduces fatigue and helps you have more energy.
- It can help lower anxiety and depression.
- It can make you feel happier.
- It helps you feel better about yourself.

And long term, we know that getting regular physical activity plays a role in helping to lower the risk of some cancers, as well as having other health benefits.

Can I lower my risk of Waldenstrom macroglobulinemia progressing?

Most people want to know if there are specific lifestyle changes they can make to reduce their risk of cancer progressing or coming back. Unfortunately, for most cancers there isn't much solid evidence to guide people. This doesn't mean that nothing will help — it's just that for the most part this is an area that hasn't been well studied. Most studies have looked at lifestyle changes as ways of preventing cancer in the first place, not slowing it down or preventing it from coming back.

At this time, not enough is known about Waldenstrom macroglobulinemia (WM) to say for sure if there are things you can do that will be helpful. Adopting healthy behaviors such as not smoking, eating well, and staying at a healthy weight might help, but no one knows for sure. However, we do know that these types of changes can have positive effects on your health that can extend beyond your risk of WM or other cancers.

So far, no dietary supplements of any kind have been shown to clearly help lower the risk of WM progressing. Again, this doesn't necessarily mean that none will help, but it's important to understand that none have been proven to do so.

- [References](#)

[See all references for Waldenstrom Macroglobulinemia](#)

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How Might Having Waldenstrom Macroglobulinemia Affect Your Emotional Health?

During and after treatment, you may find yourself overcome with many different emotions. This happens to a lot of people.

You may find yourself thinking about death and dying. Or maybe you're more aware of the effect the cancer has on your family, friends, and career. You may take a new look at your relationships with those around you. Unexpected issues may also cause concern. For instance, you might be stressed by the costs of your treatment. You might also see your health care team less often and have more time on your hands. These changes can make some people anxious.

Almost everyone who is going through or has been through cancer can benefit from getting some type of support. You need people you can turn to for strength and comfort. Support can come in many forms: family, friends, cancer support groups, religious or spiritual groups, online support communities, or one-on-one counselors. What's best for you depends on your situation and personality. Some people feel safe in peer-support groups or education groups. Others may feel more at ease talking one-on-one with a trusted friend or counselor. Whatever your source of strength or comfort, make sure you have a place to go with your concerns.

The cancer journey can feel very lonely. It's not necessary or good for you to try to deal with everything on your own. And your friends and family may feel shut out if you don't include them. Let them in, and let in anyone else who you feel may help. If you aren't sure who can help, call your American Cancer Society at 1-800-227-2345 and we can put you in touch with a group or resource that may work for you. You may also want to see [Coping with Cancer](#) for more information.

- [References](#)

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If Treatment for Waldenstrom Macroglobulinemia Stops Working

If Waldenstrom macroglobulinemia (WM) keeps growing or comes back after one kind of treatment, [other treatments](#) can often still be helpful. [Clinical trials](#) also might offer chances to try newer treatments that could be helpful.

But when a person has tried many different treatments and the WM is no longer getting better, even newer treatments may no longer be helpful. If this happens, it's important to weigh the possible limited benefits of trying a new treatment against the possible downsides, including treatment side effects. Everyone has their own way of looking at this.

This is likely to be the hardest part of your battle with cancer — when you have been through many treatments and nothing's working anymore. Your doctor might offer you new options, but at some point you may need to consider that treatment is not likely to improve your health or change your outcome or survival.

If you want to continue to get treatment for as long as you can, you need to think about the odds of treatment having any benefit and how this compares to the possible risks and side effects. Your doctor can estimate how likely it is the cancer will respond to treatments you're considering. For instance, the doctor may say that more treatment might have about a 1 in 100 chance of working. Some people are still tempted to try this. But it's important to have realistic expectations if you do choose this plan.

Palliative care

No matter what you decide to do, it's important that you feel as good as you can. Make sure you are asking for and getting treatment for any symptoms you might have, such as nausea or pain. This type of treatment is called [palliative care](#).

Palliative care helps relieve symptoms, but it is not expected to cure the disease. It can be given along with cancer treatment, or can even be cancer treatment. The difference is its purpose — the main goal of palliative care is to improve the quality of your life, or

help you feel as good as you can for as long as you can. Sometimes this means using drugs to help with symptoms like [pain](#) or [nausea](#). Sometimes, though, the treatments used to control your symptoms are the same as those used to treat cancer. For instance, [radiation](#) might be used to help relieve pain caused by a large tumor. Or [chemo](#) might be used to help shrink a tumor and keep it from blocking the bowels. But this is not the same as treatment to try to cure the cancer.

Hospice care

At some point, you may benefit from hospice care. This is special care that treats the person rather than the disease; it focuses on quality rather than length of life. Most of the time, it is given at home. Your cancer may be causing problems that need to be managed, and hospice focuses on your comfort. You should know that while getting hospice care often means the end of treatments such as chemo and radiation, it doesn't mean you can't have treatment for the problems caused by the cancer or other health conditions. In hospice the focus of your care is on living life as fully as possible and feeling as well as you can at this difficult time. You can learn more about hospice in [Hospice Care](#).

Staying hopeful is important, too. Your hope for a cure may not be as bright, but there is still hope for good times with family and friends — times that are filled with happiness and meaning. Pausing at this time in your cancer treatment gives you a chance to refocus on the most important things in your life. Now is the time to do some things you've always wanted to do and to stop doing the things you no longer want to do. Though the cancer may be beyond your control, there are still choices you can make.

You can learn more about the changes that occur when treatment stops working, and about planning ahead for yourself and your family, in [Advance Directives](#) and [Nearing the End of Life](#).

- [References](#)

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1-800-227-2345 or www.cancer.org