After Acute Myeloid Leukemia Treatment

Living as an AML Survivor

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

- What Happens After Treatment for Acute Myeloid Leukemia?
- Lifestyle Changes After Treatment for Acute Myeloid Leukemia
- How Might Treatment for Acute Myeloid Leukemia Affect Your Emotional Health?

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 Acute Myeloid Leukemia Stops Working

What Happens After Treatment for Acute Myeloid Leukemia?

For some people with acute myeloid leukemia (AML), treatment can destroy the leukemia cells. Completing treatment can be both stressful and exciting. You may be relieved to finish treatment, but find it hard not to worry about the leukemia coming back. (When leukemia comes back after treatment, it is called recurrence.) This is a very common concern in people who have had cancer.

It may take a while before your fears lessen. But it may help to know that many leukemia survivors have learned to live with this uncertainty and are leading full lives. See Understanding Recurrence for more about this.
For other people, the leukemia may never go away completely. These people may get regular treatments with chemotherapy or other therapies to try to help keep the leukemia under control and help relieve symptoms from it. Learning to live with leukemia that does not go away can be difficult and very stressful. It has its own type of uncertainty. See Managing Cancer As a Chronic Illness for more about this.

Follow-up care

Treatment for acute myeloid leukemia (AML) can continue for months or years. Even after treatment ends, you will need frequent follow-up exams – probably every few months for several years. It’s very important to go to all of your follow-up appointments. During these visits, your doctor will ask about any symptoms, examine you, and get blood tests or bone marrow exams. Follow-up is needed to check for cancer recurrence, as well as possible side effects of certain treatments.

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

If the leukemia does come back, it is usually while the patient is still being treated or shortly after they have finished chemotherapy. If this happens, treatment would be as described in What if the leukemia doesn’t respond or comes back after treatment? It is unusual for AML to return if there are still no signs of the disease within a few years after treatment.

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

Should your cancer come back, see Understanding Recurrence for information on how to manage and cope with this phase of your treatment.

Seeing a new doctor

At some point after your treatment, you may be seeing a new doctor who doesn't know anything about your medical history. It's important to 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
• 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 or other medicines, a list of your drugs, drug doses, and when you took them
• The names and contact information of the doctors who treated your cancer

References

See all references for Acute Myeloid Leukemia

Lifestyle Changes After Treatment for Acute Myeloid Leukemia

You can’t change the fact that you have had leukemia. 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 treatment.

Making healthier choices

For many people, a diagnosis of leukemia 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 for information and support. Our tobacco cessation and coaching service can help increase your chances of quitting for good.

**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 may 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 intake can lower your risk for a number of types of cancer, as well as having many other health benefits.

To learn more, see [Nutrition for the Person With Cancer During Treatment: A Guide for Patients and Families](#).

**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 be active and do the 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. 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 and Anemia in 
People With Cancer.

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.

Getting regular physical activity also 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 acute myeloid leukemia progressing or coming back?**

Most people want to know if they can make certain lifestyle changes 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 AML to say for sure if there are things you can 
do that will help. Healthy behaviors such as not smoking, eating well, and staying at a 
healthy weight might help, but no one knows for sure. But we do know that these types 
of changes can have positive effects on your health that can extend beyond your risk of 
AML or other cancers.

So far, no dietary supplements have been shown to clearly help lower the risk of AML 
progressing or coming back. Again, this doesn’t mean that none will help, but it’s
important to know that none have been proven to do so.

- References
  See all references for Acute Myeloid Leukemia

How Might Treatment for Acute Myeloid Leukemia 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 leukemia 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 over time 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 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 read Distress in People with Cancer for more information.

- References
See all references for Acute Myeloid Leukemia

If Treatment for Acute Myeloid Leukemia Stops Working

If the leukemia keeps growing or comes back after one kind of treatment, it is possible that another treatment plan might still cure it, or at least keep it under control enough to help you live longer and feel better (see What if acute myeloid leukemia doesn’t respond or comes back after treatment?). 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 leukemia 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 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 leukemia – 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. In many cases, your doctor can estimate how likely it is the leukemia will respond to treatment you are 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 is 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’s 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.

For leukemia, palliative care often includes treatments such as _blood transfusions_ that help relieve fatigue. Sometimes, though, the treatments used to control your symptoms are the same as those used to treat the leukemia. For instance, radiation might be used to help relieve bone pain. Or chemo might be used to help keep the number of leukemia cells in check. But this is not the same as treatment to try to cure the leukemia.

**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 leukemia 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 leukemia 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 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 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 leukemia 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**
[See all references for Acute Myeloid Leukemia](#)

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