

KNOW AML Interactive guide

Navigating life after treatment for acute myeloid leukemia

*Managing the long-term
effects on your* **Body**  *&
Mind*

START





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contents page



Welcome to our interactive guide

Understanding the long-term effects of acute myeloid leukemia treatment is essential for patients and their loved ones. This guide is designed to help you understand the effects on the body and mind, provide ways to cope, and help improve overall quality of life.

Chapter one

What are long-term effects of treatment?

Chapter two

Long-term effects of treatment on your body

Chapter three

Long-term effects of treatment on your mind

Chapter four

Ways to cope and further resources

Click on the
shapes with
shadows to
find out more
information

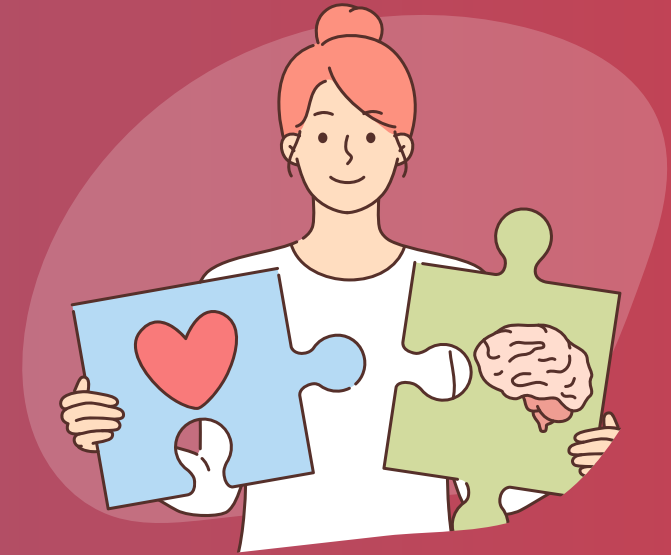
Move through
this guide using
the arrows





Chapter one

What are long-term effects of treatment?



Let's discover what long-term effects of treatment for acute myeloid leukemia are, how likely you are to experience them, and find out the truth behind some common misconceptions.

NEXT





What are long-term effects of treatment for acute myeloid leukemia?

Long-term effects of acute myeloid leukemia treatment are health issues that can develop weeks, months, or years after the treatment is finished.

You may feel happy and relieved when your treatment ends, and it is natural to hope you will quickly feel “normal” again.

However, this feeling may not last, and it is important to take things gently and not rush yourself. It may take some time to heal physically and emotionally after treatment.





How likely are you to experience long-term effects of treatment?

Your likelihood of experiencing long-term effects can be influenced by factors such as:

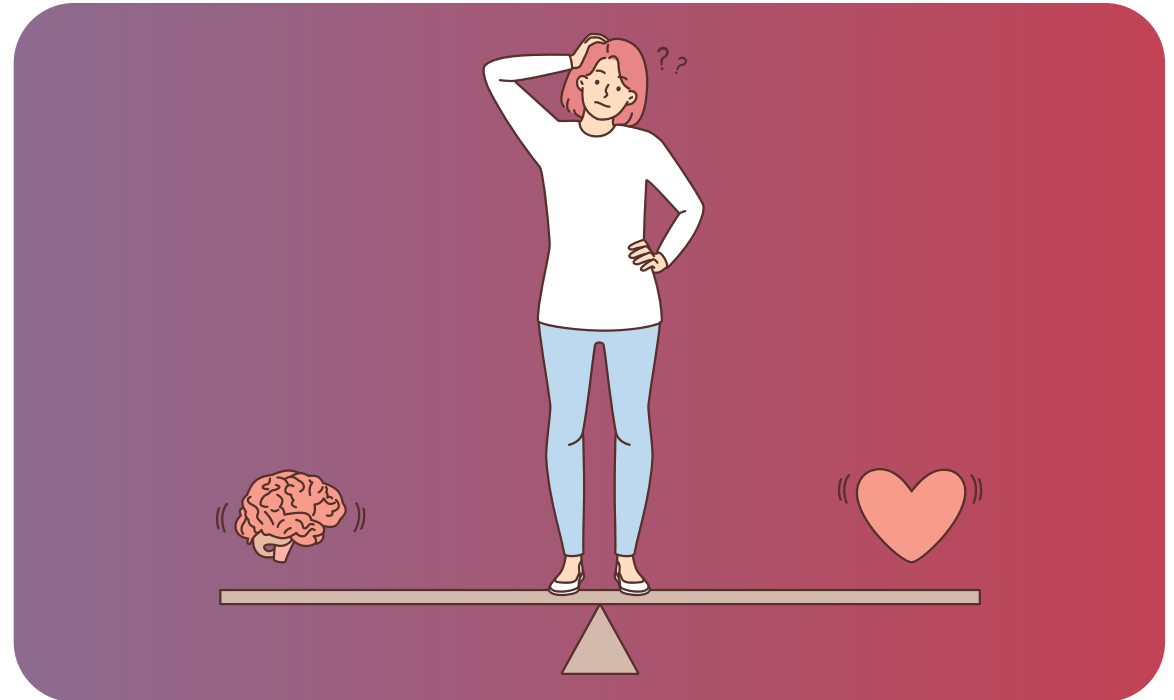
The type of treatment you received

The duration and intensity of treatment

Your sex

Your age

Your overall health





How likely are you to experience long-term effects of treatment?

Your likelihood of experiencing long-term effects can be influenced by factors such as:

The type of treatment you received

The duration and intensity of treatment

Your sex

Your age

Your overall health

It is important to discuss treatment benefits and risks with your healthcare team.

Chemotherapy may increase the risk of heart problems and infections.

Stem cell transplants may lead to graft-versus-host disease, weakened immunity, infertility, diabetes, lung issues, and secondary cancers.

Total body irradiation may cause osteoporosis, heart and thyroid problems, and diabetes.





How likely are you to experience long-term effects of treatment?

Your likelihood of experiencing long-term effects can be influenced by factors such as:

The type of treatment you received

The duration and intensity of treatment

Your sex

Your age

Your overall health

Longer and more intensive treatment can increase the risk of side effects, including organ damage, cognitive decline, fertility issues, low resistance to infections, and the development of secondary cancers.





How likely are you to experience long-term effects of treatment?

Your likelihood of experiencing long-term effects can be influenced by factors such as:

The type of treatment you received

The duration and intensity of treatment

Your sex

Your age

Your overall health

In men, certain treatments may affect the testes, the quality and quantity of sperm, and the production of hormones that support fertility.

In women, treatment can impact the ovaries and womb, disrupt hormone levels, and increase the risk of early menopause and bone thinning (osteoporosis).





How likely are you to experience long-term effects of treatment?

Your likelihood of experiencing long-term effects can be influenced by factors such as:

The type of treatment you received

The duration and intensity of treatment

Your sex

Your age

Your overall health

Older patients may experience more long-term effects due to reduced physical strength, organ dysfunction, a weaker immune system, and comorbidities.

Children may experience delays in growth.

Fertility may be impacted in patients of reproductive age.





How likely are you to experience long-term effects of treatment?

Your likelihood of experiencing long-term effects can be influenced by factors such as:

The type of treatment you received

The duration and intensity of treatment

Your sex

Your age

Your overall health

If you have other health conditions, such as heart disease, kidney problems, or diabetes, you may be at increased risk of long-term side effects, for instance, organ damage, infections, secondary cancers, or fatigue.





Common misconceptions about the long-term effects of treatment

Once treatment ends, all side effects disappear.

TRUE

FALSE

There is no need for long-term monitoring if you feel healthy.

TRUE

FALSE

You will be able to return to normal life.

TRUE

FALSE





Chapter one

Common misconceptions about the long-term effects of treatment

Once treatment ends, all side effects disappear.

TRUE

FALSE

False: While some side effects may resolve shortly after treatment, many biological and emotional effects can last longer, particularly after chemotherapy or a stem cell transplant.

BACK





Chapter one

Common misconceptions about the long-term effects of treatment

False: Treatment can sometimes lead to side effects that only become apparent after some time. Long-term monitoring is needed to pick these up and treat them early.

There is no need for long-term monitoring if you feel healthy.

TRUE

FALSE

BACK





Common misconceptions about the long-term effects of treatment

True: It may take time and support, but with the right care, you can regain strength and independence and find new ways to live a fulfilling life. Although your life may not be exactly as it was before, this time is about discovering and embracing your 'new normal'.

BACK

NEXT

You will be able to return to normal life.

TRUE

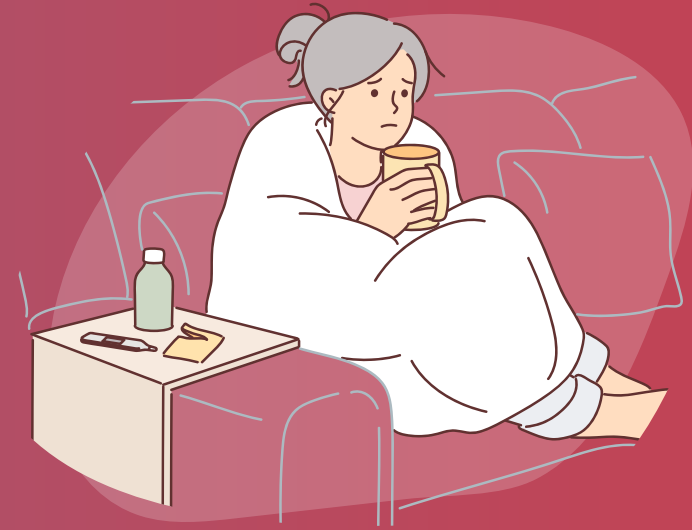
FALSE





Chapter two

Long-term effects of treatment on your body



Now that we understand what long-term effects of treatment for acute myeloid leukemia are, let's look at how some of these can affect your body.

NEXT





What long-term effects might you experience that affect your body?

Fertility issues
and early
menopause

Secondary
cancers

Lung
problems

Fatigue

Low resistance to
infections

Heart
problems

Thyroid problems

Osteoporosis

Diabetes

Growth delays in
children





What long-term effects might you experience that affect your body?

Fertility issues and early menopause

Secondary cancers

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Fatigue

Low resistance to infections

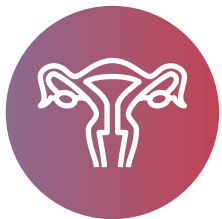
Heart problems

Thyroid problems

Osteoporosis

Diabetes

Growth delays in children



Some treatments for acute myeloid leukemia can affect fertility in men and women. If you are considering having children, discuss fertility preservation options with your healthcare team before starting treatment. Certain treatments may also cause early menopause in women. Let your healthcare team know if you experience menopause symptoms, such as hot flashes, sweating, vaginal dryness, feeling sad or depressed, joint pains, muscle aches, weakening of the bones, or loss of interest in sex.





What long-term effects might you experience that affect your body?

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**Secondary
cancers**

Lung
problems

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Low resistance to
infections

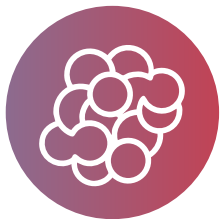
Heart
problems

Thyroid problems

Osteoporosis

Diabetes

Growth delays in
children



There is a slight increase in the risk of developing another type of cancer following certain treatments for acute myeloid leukemia, such as total body irradiation before a stem cell transplant. Regular medical follow-ups are crucial for early detection and management of new health issues.





Chapter two

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and early
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cancers

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problems**

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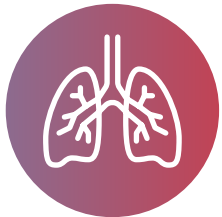
Heart
problems

Thyroid problems

Osteoporosis

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Growth delays in
children



There is a slight increase in the risk of developing inflammation in the lungs after a stem cell transplant. Let your healthcare team know if you experience breathlessness or develop a long-term cough.





Chapter two

What long-term effects might you experience that affect your body?

Fertility issues and early menopause

Secondary cancers

Lung problems

Fatigue

Low resistance to infections

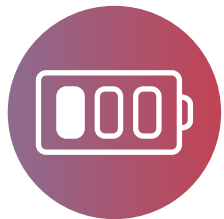
Heart problems

Thyroid problems

Osteoporosis

Diabetes

Growth delays in children



Fatigue (tiredness) after treatment for acute myeloid leukemia can last for months or sometimes years. You may need tests to check for causes, such as low thyroid function or anemia, or to see if exercise may help.





What long-term effects might you experience that affect your body?

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menopause

Secondary
cancers

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**Low resistance to
infections**

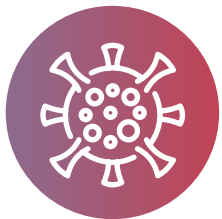
Heart
problems

Thyroid problems

Osteoporosis

Diabetes

Growth delays in
children



Your immune system may take a while to fully recover after treatment. If you have low levels of white blood cells, your body will find it harder to fight off infections. Let your healthcare team know if you experience any symptoms of an infection, such as a sore throat, cough, frequent diarrhea, vomiting, dizziness, headache, feeling hot or cold, or a new pain anywhere in your body.





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problems**

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children



Some treatments, such as chemotherapy or radiotherapy, can cause heart problems, which may develop during treatment or years later. If you notice symptoms such as tiredness, swollen ankles, a fluttering feeling in your chest, shortness of breath, or chest pain, let your healthcare team know.





Chapter two

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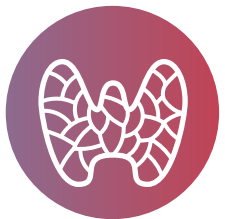
Heart
problems

Thyroid problems

Osteoporosis

Diabetes

Growth delays in
children



Occasionally, the thyroid gland can be affected by radiotherapy. Let your healthcare team know if you experience a lack of energy, constipation, weight gain, or feel cold more often than usual.





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children



Some treatments for acute myeloid leukemia, such as total body irradiation, steroids, or lower levels of hormones, can cause thinning of your bones. Your healthcare team will monitor you for signs of this.





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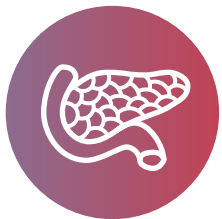
Heart
problems

Thyroid problems

Osteoporosis

Diabetes

Growth delays in
children



Radiotherapy can cause damage to your pancreas (an organ which helps regulate blood sugar levels). Let your healthcare team know if you experience any of the following symptoms: increased thirst, tiredness, hunger, slow healing of wounds, blurred vision, or frequent urination.





Chapter two

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Low resistance to infections

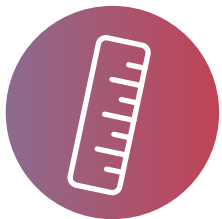
Heart problems

Thyroid problems

Osteoporosis

Diabetes

Growth delays in children



Children undergoing treatment for acute myeloid leukemia may face growth delays or developmental challenges. Regular assessments and early interventions, including physical therapy and educational support, can help with these issues.





Chapter three

Long-term effects of treatment on your mind



It is just as important to be aware of changes to your mind as well as your body, so now let's look at symptoms you might experience that could affect your mental health and your cognitive skills.

NEXT





How might your mental health be affected?

Your mental health may be affected after treatment for acute myeloid leukemia, and it's important to talk about your psychological symptoms with family, friends, and your healthcare provider so they can help. Some long-term psychological effects you might experience are:

Depression

Anxiety

Post-traumatic stress





How might your mental health be affected?

Your mental health may be affected after treatment for acute myeloid leukemia, and it's important to talk about your psychological symptoms with family, friends, and your healthcare provider so they can help. Some long-term psychological effects you might experience are:

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Post-traumatic stress

Depression is common at any stage of treatment, and it can sometimes continue after treatment is over. Symptoms of depression include changes in appetite, sleep disturbances, fatigue, decreased concentration and short-term memory, reduced libido, feeling discouraged, loss of interest in people and activities, feelings of guilt, helplessness, worthlessness and irritability, negative thoughts about oneself and the future, and, in severe cases, suicidal thoughts. If you think you might be depressed, reach out to your healthcare team.





How might your mental health be affected?

Your mental health may be affected after treatment for acute myeloid leukemia, and it's important to talk about your psychological symptoms with family, friends, and your healthcare provider so they can help. Some long-term psychological effects you might experience are:

Depression

Anxiety

Post-traumatic stress

It is normal to be worried about the success and outcome of treatment, as well as the possibility of the cancer returning. However, if these thoughts become difficult to manage or begin to interfere with your quality of life and daily functioning, talk to your healthcare team about referral for medication and psychotherapy.





How might your mental health be affected?

Your mental health may be affected after treatment for acute myeloid leukemia, and it's important to talk about your psychological symptoms with family, friends, and your healthcare provider so they can help. Some long-term psychological effects you might experience are:

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The hospitalization and acute recovery following a stem cell transplant, which differs from other cancer treatments, can be traumatic and may contribute to post-traumatic stress. Even long after treatment, you may still find yourself reliving your cancer and treatment experiences, with nightmares, flashbacks, or persistent thoughts about the procedures. If you think you are experiencing post-traumatic stress reaction, reach out to your healthcare team.





What long-term cognitive changes might you experience?

You may also notice changes in your memory, way of thinking, and ability to concentrate. These changes are called mild cognitive impairment or cognitive dysfunction, often known as “chemo brain” or “chemo fog”. Common symptoms include:

Forgetting things you would usually remember

Struggling to find the right word or name for something

Having trouble following conversations

Difficulty focusing or concentrating on one task

Finding it hard to multitask

Having trouble with tasks that used to be easy, such as doing simple sums in your head

Feeling confused or disoriented

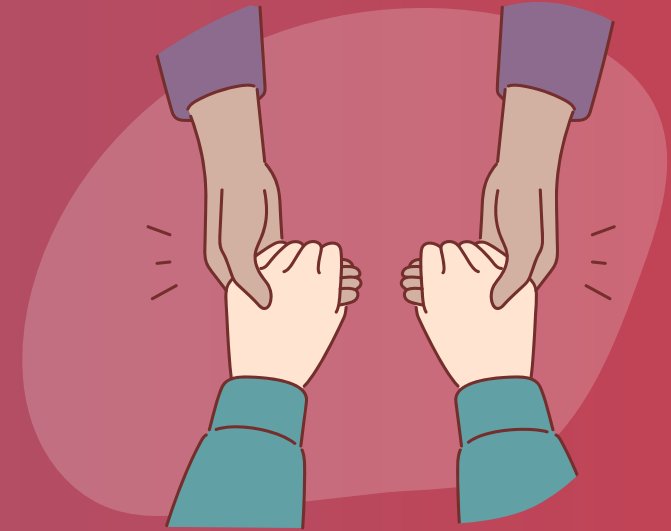
Experiencing mental cloudiness





Chapter four

Ways to cope and further resources



Now that you understand more about the impact treatments can have on your body and mind in the long term, let's explore different ways to help cope with these effects.

NEXT





Coping with long-term effects of treatment

Talk to your healthcare team and discuss the challenges you are facing. They may recommend:

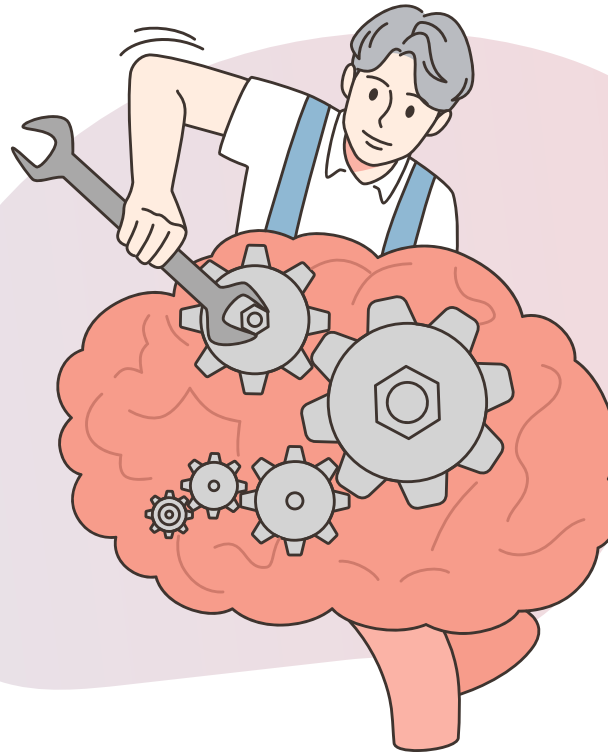


Cognitive training

Physical activity



Talking therapies



Mind-body training

Medications



Nutrition advice





Chapter four

Coping with long-term effects of treatment: Self-help tips to manage cognitive changes

Use a reminder system, such as a calendar, daily planner, or mobile app, to keep track of your appointments

Always place important items, such as your car keys, phone, and planner, in the same place so you can easily find them

Try to limit distractions when focusing on tasks

Aim to get some movement or exercise every day, if possible

Allow yourself extra time to complete tasks, both personal and at work

Avoid trying to do multiple things at once

Avoid alcohol or substances that can affect your thinking

Ask for help when you need it

Be open and honest with your healthcare team, family, and friends about any challenges you are facing



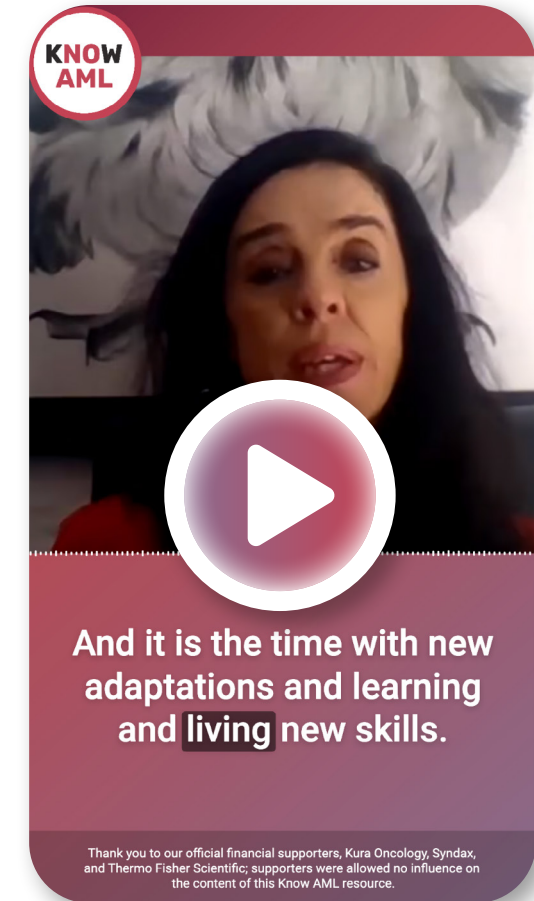


Coping with long-term effects of treatment

Mental health

Keep a record of any symptoms you experience that are affecting your mental health. Communicate openly with your healthcare team, as well as with your family and loved ones.

Watch: Vanessa Marais, a clinical psychologist from South Africa, discusses ways to look after your mental health during different stages of acute myeloid leukemia.



[CLICK TO WATCH](#)






Coping with long-term effects of treatment

Nutrition

A healthy diet can support your body to heal and maintain your strength.

Watch: Katie Walker, a dietitian at King's College Hospital NHS Foundation Trust in the United Kingdom, discusses food recommendations for patients after a transplant to prevent long-term complications.



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build up that lean tissue because that's **what** helps you feel stronger and able to get more active again.

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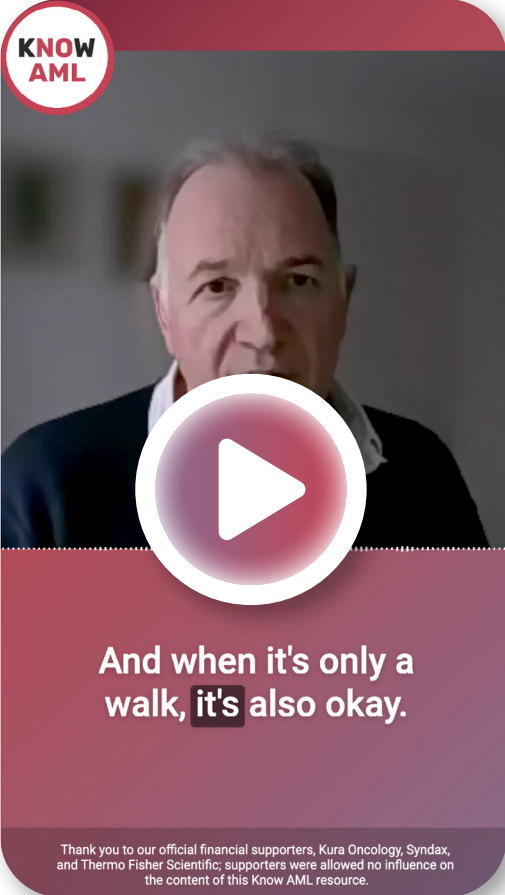


Coping with long-term effects of treatment

Physical activity

Engage in regular physical exercise and movement when approved by your healthcare team.

Watch: Erik Aerts, a specialist nurse from the University of Zurich in Switzerland, discusses the importance of physical exercise after treatment.



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And when it's only a walk, **it's** also okay.

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CLICK TO WATCH





Coping with long-term effects of treatment

Other self-care measures

Avoid smoking and ensure you are getting enough sleep. Consider trying complementary therapies, such as yoga, breathing exercises, acupuncture, aromatherapy, massage, and meditation.

Watch: Charlotte Tottman, a clinical psychologist from Australia specializing in cancer-related distress, discusses how self-care measures can aid in managing the side effects of chemotherapy and in living with acute myeloid leukemia.

KNOW AML

And, for some of us, one of those pillars might be more important than others.

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CLICK TO WATCH



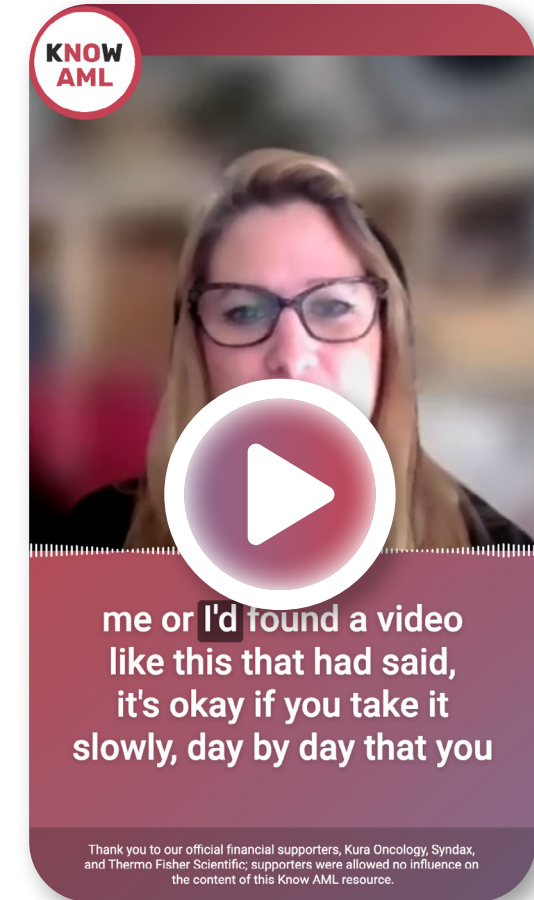


Coping with long-term effects of treatment

Peer support

Connect with others who have been through acute myeloid leukemia. You can watch personal stories from our Know AML ambassadors where they share how they cope with the long-term effects of their treatment.

Watch: Anna Mamwell, a Know AML ambassador from the United Kingdom, shares her journey of embracing and adapting to a 'new normal'.



[CLICK TO WATCH](#)






Coping with long-term effects of treatment

Talking therapies

It can help to talk to a counselor, therapist, or social worker. You can also connect with others who have been through the same experiences, for example via a cancer support group, one-on-one peer support, or an online virtual group.

Watch: Melanie Stachelski, a cancer counselor, psychotherapist, and acute myeloid leukemia survivor from the United States, discusses practices to help manage mental health.



KNOW AML

There are support groups that are disease specific, so **specifically** for AML or other blood cancers.

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CLICK TO WATCH





Resources, support, and further reading



Know-AML.com

On our website you can learn more about acute myeloid leukemia and hear from the healthcare professionals, patients, and caregivers about how they manage the condition.

Patient advocacy groups

Leukemia & Lymphoma Society (LLS)

American Cancer Society (ACS) Cares

CancerCare

City of Hope

Leukemia Foundation

Cancer Support Community

Peer support groups

Leukemia Research Foundation Online Support Community

Smart Patients AML Community

Blood Cancer UK Online Community Forum

Leukemia & Lymphoma Society First Connection Program





Chapter four

Would you like to learn more about nutrition, wellbeing, and psychological support, as well as movement and exercise? We've compiled a list of websites and resources to support you on your journey.

[Know-AML.com/keep-moving-keep-learning](https://www.know-aml.com/keep-moving-keep-learning)

KEEP MOVING
Keep learning



[Download the pdf version](#)





END

We hope you found our guide helpful!
Please share with others who may find this resource useful too.

[View references](#)





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