



Survivorship

Resources

Next Steps Survivorship Program



MACC Fund Center
for Cancer & Blood Disorders



Our goal is to help survivors live **happy, healthy lives.**

Knowledge is Power

This book gives education, resources and tips to keep you healthy. You can find the information you need by checking these sections:

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Transitioning to a “new” normal

Parents and survivors of cancer or bone marrow transplant (BMT), often wonder about the survivors’ health and future well-being.

This clinic helps patients and families:

- Watch for possible late effects (a health problem that can happen after treatment ends)
- Learn ways to live a healthy lifestyle based on risk factors
- Speak up or advocate for patient’s health.

During clinic, we will review your treatment history and follow the Children’s Oncology Group (COG) Survivorship Guidelines to watch for late effects. The team will review with you the treatment you had and what late effects to screen for.

Find more information by looking at the health links, which are tip sheets to help you understand each late effect and what follow-up is recommended. These can be found on the COG website at survivorshipguidelines.org.



Healthy Living Tips

There are things you can do to support a healthy lifestyle. Making healthy lifestyle choices affects your quality of life and may be easier than you think. We will discuss what choices are best for your life.

Healthy Eating & Limit Alcohol

- Get to a healthy weight. Stay at a healthy weight.
- Eat healthy, including fruits and vegetables. The dietitian can help with ideas and a plan that works for you.
- Use **choosemyplate.gov** as a resource.
- Limit drinking sugary and alcoholic drinks.

Increase Physical Activity

Stay active with regular physical activity. Physical activity can lower the risk of many types of diseases.

Stay Away from Tobacco

There is no safe form of tobacco. Smoking or vaping increases the cancer risk for smokers and everyone near them. There are tools to help you quit. There are many resources, including **cancer.org/smokeout**.

Protect Your Skin

- Prevent skin cancer by using sun protection.
- Stay out of direct sun and tanning beds
- Wear broad-spectrum sunscreen with SPF 30 or higher, wide-brimmed hats and sunglasses.
- Look at your skin monthly. If you notice any changes to moles and spots on your skin, report them to your doctor.



Regular Screening Prevention

It is important to set up care with a primary care provider. They will take care of your health needs.

You should:

- Have regular checkups and cancer screenings.
- Be aware of any changes in your body.

You can set up care with Children's Medical Group at **childrenswi.org/primarycare**. If you need help finding an adult doctor, contact our team.

If you had radiation to the chest, the risk of cancer is higher for you than it is for others your age who did not have radiation.

Breast Self-Exam

- Check your breasts monthly.
- Report any lumps or changes to your doctor right away.
- Have your doctor do a breast exam, at least yearly.
- Your doctor may suggest a mammogram or breast MRI.

Testicular Self-Exam

- Check your testicles monthly.
- Report any lumps or changes to your doctor right away.



Fertility Awareness

Some survivors are at risk for infertility. This means they are unable to get pregnant or have a child naturally. Your risk can depend on:

- The type of chemotherapy, surgery or radiation you had
- The age and stage of puberty when diagnosed
- The type of cancer, blood or autoimmune disorder

Fertility will be talked about at diagnosis and during your survivorship visits. There may be options to save your fertility before or after treatment ends.

Some treatments may affect the hormones needed for growth and developing your body. Your doctor may suggest a blood test to check your levels.

Our team will help you make the best decision for your fertility. We may send you to see a specialist to help you learn more about your options.

Contact Fertility Navigator, Katy Tomlinson, BSN, RN, in the Next Steps Survivorship Clinic at Children's Wisconsin if you have questions.

ktomlinson@chw.org | 414-266-3712

Bone Marrow Transplant Resources

If you had a bone marrow transplant, regular follow-up care is needed. There are resources for patients who had a bone marrow transplant. These resources give information on:

- Late effects (a health problem that can happen after treatment ends)
- Financial support
- Ways to speak up for your health

The Bone Marrow Foundation

bonemarrow.org

This resource offers financial help and free support services to cancer and transplant patients and their families.

Blood and Marrow Transplant Information Network

bmtinfonet.org

This resource helps you learn about late effects after your transplant. They also connect patients and families with others who have had a transplant.

National Marrow Donor Program

bethematch.org

This resource provides transplant education, one-on-one support to patients and their families and continued research.

Pediatric Blood & Marrow Transplant Consortium

pbmtc.org

This resource supports research and education. Their goal is to learn about other treatments besides bone marrow transplant to treat cancer, blood or autoimmune disorders.

School Resources

After cancer or a bone marrow transplant, you may have both short and long-term effects from treatment. Some of these side effects may change how you learn.

Schools have resources to help children who have special learning needs. Individualized Education Plans (IEPs) and Section 504 plans are examples of these resources. These resources support children's specific learning needs.

Some patients may need special testing to support these plans. This testing is called neuropsychology testing. This test checks how the health of your brain is impacting your thinking or behavior.

If you think you have learning needs, talk with our team. We will figure out which resources would work best for you.

Scholarship Opportunities

A scholarship is an award you can apply for to help pay for school. There are scholarships to support financial needs for patients who have had cancer and their siblings. These are for those who plan to attend a technical 2-year school, 4-year accredited school or graduate school.

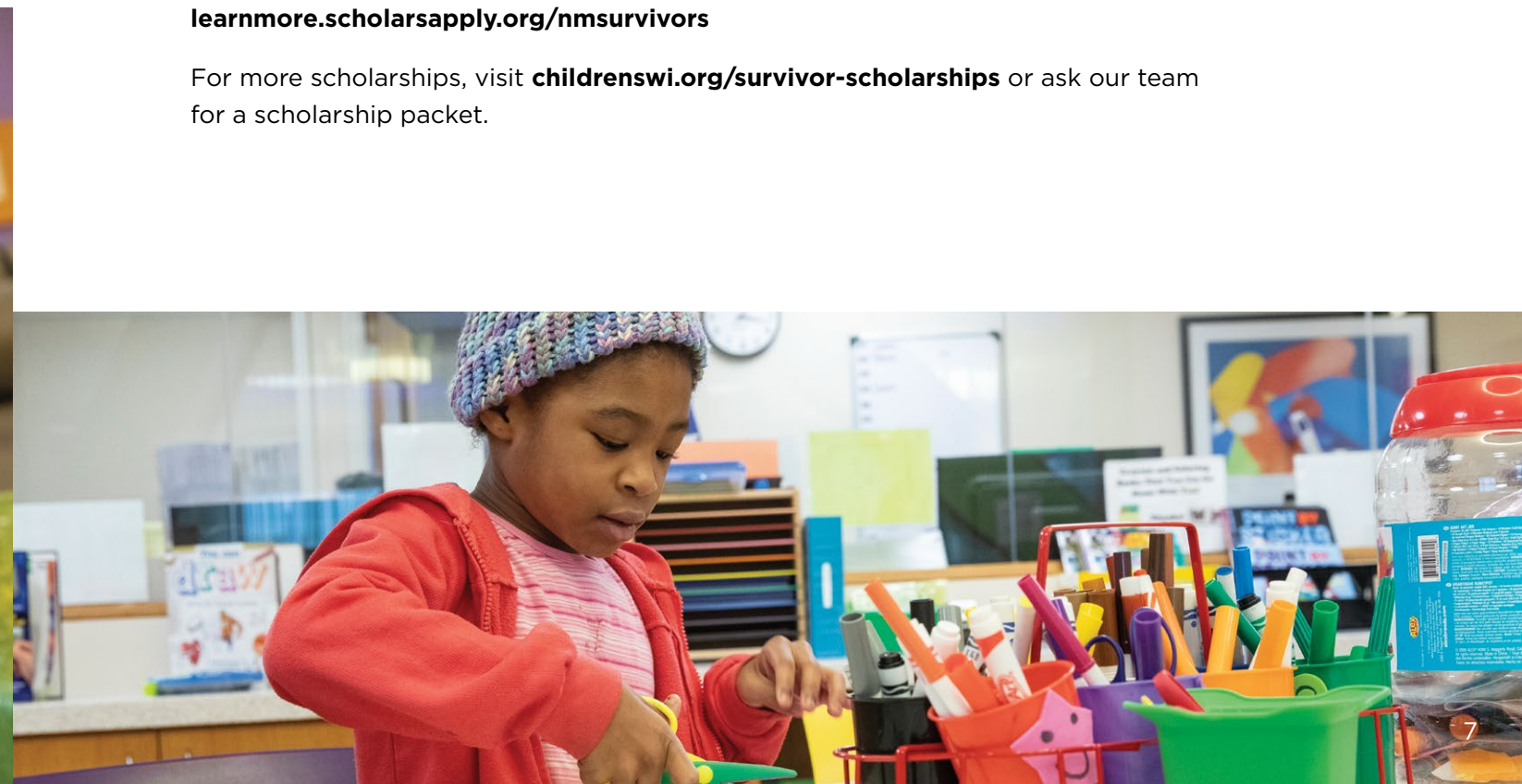
Beyond the Cure Ambassador Scholarship Program

thencs.org/scholarship

Northwestern Mutual Childhood Cancer Survivor Scholarship Program

learnmore.scholarsapply.org/nmsurvivors

For more scholarships, visit **childrenswi.org/survivor-scholarships** or ask our team for a scholarship packet.



Speak Up for Your Health

Cancer or having a bone marrow transplant changes your life in many ways. You may have hard times from your treatment. Because of this, you should:

- Advocate or speak up for yourself.
- Take charge of your health and your healthcare needs.
- Speak with your team about any questions or concerns.
- Use the questions on the next page to help advocate for your own health.

The person who speaks best for you is you.

- Do you know your treatment history?
- Do you know the possible late effects from your treatment?
- Do you have any late effects?
- Do you feel comfortable talking to doctors about your treatment history and possible late effects?
- Do you know where your treatment summary or passport is located?
- Do you give your treatment summary or passport to new doctors to help them better understand your history?
- Do you make an appointment with your primary care doctor at least once a year?
- Do you partner with your doctor on decisions for your health?
- Do you ask for privacy during a discussion or an exam? You have the right to ask anyone to leave the room if you will feel uncomfortable.
- Do you know how to connect with other patients and survivors?
- Do you know how to connect with community supports (Psychology, Social Work, Child Life, Financial Counseling, School/Work)?





Expanding the Circle of Support for Survivors

General Resources

American Cancer Society

cancer.org

Gives general support, education and research.

Leukemia & Lymphoma Society

lls.org

Gives money for research and provides support to treatments for blood cancer patients.

The National Children's Cancer Society

thencs.org

Gives information before and after treatment, financial help and support.

The Sam Fund

thesamfund.org

Peer and financial support for teen and young adult cancer survivors.

Sarcoma Foundation of America

curesarcoma.org

Speaks up for sarcoma patients with giving money for research and telling others.

Stupid Cancer

stupidcancer.org

Nonprofit that supports young adult cancer patients.

Camps & Adventure Programs

One Step at a Time Programs

camonestep.org

Camp for children up to age 19, sibling camp and family camp.

First Descents

firstdescents.org

Camp for young adults (18 & up); offers outdoor sports.

Careers

Cancer and Careers

cancerandcareers.org

Gives advice and educates about cancer and your job.

Workforce Development— Vocational Rehabilitation

dwd.wisconsin.gov/dvr

Physical Activity

Kids Kicking Cancer

kidskickingcancer.org/program/us/wisconsin

Gives martial arts classes for children and teens.

Livestrong at the YMCA

gwcymca.org/LIVESTRONG-at-the-YMCA

A program to help adult cancer survivors (18 and up) get back to their health.

Support

Imerman Angels

imermanangels.org

Connects those fighting cancer with a survivor of the same cancer. Also supports family needs.

Young Adult Oncology Group

childrenswi.org/young-adult-onc-group

Gives young adults the chance to share experiences. They meet monthly at social events. Join on Facebook, search "YAOG Midwest Wisconsin."

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childrenswi.org/onc-survivorship



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