

Hematology Caregivers: A Guide to Available Resources

Patients undergoing cellular therapy require a personal caregiver to assist them during their treatment and recovery. During the planning stages of transplant, it should be established who the primary caregiver will be. Caregivers are most often a family member or close friend — they must be able to responsibly provide physical care, perform observations and lend emotional support.

Caregiver role

The caregiver is part of the health care team, which also includes the patient and medical staff.

Caregivers do many things, including:

- Providing or making arrangements for transportation to and from appointments
- Keeping track of the patient's schedule/ medications
- Providing emotional support
- Providing physical care (**delivering oral medications, identifying changes in patient condition, obtaining medical care when necessary and reporting symptoms to medical staff**)
- Maintaining the home environment (cleaning, preparing food, providing opportunities for the patient to rest)
- Gathering information and researching treatment options; guiding decision making
- Managing insurance and finances
- Communicating with other family members and friends (organizing meal deliveries, coordinating visitors, updating on patient status, delegating tasks)

Tips

- It is essential that caregivers of cellular therapy patients take care of themselves. It is normal to feel stressed, emotionally and physically.
- Nourish your body and sleep — rest when you are tired and eat healthy; get some exercise and try to stay hydrated.
- Don't be afraid to ask questions; it may be helpful during appointments to take notes. Giving updates to the many loved ones in your life can

be exhausting. Consider posting updates online and referring people to the site; assign tasks of giving updates to a friend or relative.

- Recognize your limits and remember to take breaks — enlist the help of other friends, family and community. When loved ones ask if there is anything they can do, provide them with a list of things that need doing — mowing lawn, shopping, staying with the patient while you run errands.
- Socialize and maintain your own interests, continue hobbies and activities that you enjoy. When going out with your friends, tell them that there will be no cancer talk during your outing — it's a "cancer free zone" — otherwise you will not get a mental break. They will appreciate knowing that they can talk about trivial things with you.
- Acknowledge your feelings — try to express them constructively. Caregivers report that feelings of helplessness and guilt are **very** common.
- If you need to have a good cry or vent to a loved one, tell them you need them to **listen**. They don't have to "fix" anything or tell you **it's going to be OK**.
- If/when loved ones give advice and tell you to read an article, you might say, "Thank you for your suggestion but I won't be able to get to that right now."
- Talking with others in similar situations can provide you with emotional support, encouragement and give you hope.
- Finally, you ARE doing enough, you ARE "doing it right" and you are not alone. Call a friend, join a support group, and when all else fails, go to the woods and scream.

Housing support

Swedish provides a list of recommended local hotels and lodging, available on the Swedish website. www.swedish.org/Patient-Visitor-Info/hotels-lodging

Caregiver support group

A drop-in group for caregivers facilitated by an experienced Swedish Cancer Institute oncology social worker meets weekly at Swedish First Hill. Please call for more information: 206-215-3659.

Cancer Education Center

The Cancer Education Center (CEC) is located at our Swedish Cancer Institute First Hill campus, in the Arnold Pavilion on the A-Floor (basement floor). The center is staffed with health education specialists and volunteers who offer a safe environment for patients and their caregivers. They are there to assist you with finding health education and supportive resources from cancer prevention to survivorship and everything in between.

If you would like to access online resources, such as a podcast or website, you can stop by the education center at the Swedish Cancer Institute to rent an iPad for free. Please call and/or email for more information: 206-386-3200, SCI.Education@swedish.org.

If you would like additional support, ask your nurse or oncology social worker for more information.

Websites

The websites listed below have helpful information intended to support caregivers. Click on the links for further information.

- **National BMT Link**

www.nbmtlink.org

An organization that helps patients, caregivers and families cope with the social and emotional challenges of stem cell transplant from diagnosis through survivorship by providing vital information and personalized support services.

- Peer Support On Call Program: 800-LINK-BMT (546-5268)
- Caregivers Guide for Bone Marrow/Stem Cell Transplant (online pdf booklet)
- For Better and For Worse: Impact of Cancer and BMT on Spouse-Caregivers (webcast)

- **National Marrow Donor Program**

www.marrow.org

A nonprofit organization dedicated to creating an opportunity for all patients to receive the transplant they need. For life-threatening blood cancers like leukemia and lymphoma, a cure exists.

- Be The Match Caregivers Companion Program (online pdf booklet).

- **Leukemia and Lymphoma Society**

<https://www.lls.org/support/caregiver-support>

The Leukemia & Lymphoma Society is at the forefront of the fight to cure blood cancer. They provide a lot of resources specific to caregivers including podcast, online chat, downloadable work book and worksheets.

- **Blood and Marrow Transplant Information Network**

www.bmtinfolnet.org

An organization dedicated to providing transplant patients, survivors and their loved ones with emotional support and high quality, easy-to-understand information about bone marrow, peripheral blood stem cell and cord blood transplants.

- **Family Caregiving Alliance (FCA)**

www.caregiver.org

1-800-445-8106

FCA offers the **Family Care Navigator**, the first-of-its-kind, comprehensive, online guide to help families locate caregiver support programs and services in all 50 states. It is an invaluable tool to locate information and specific services in an easy-to-read chart format. All family caregivers can use the extensive library of fact sheets, articles and checklists as well as participate in numerous webinars and videos on caregiving issues catalogued on their site.

Brochures

- **Caring for the Caregiver (NCI)**
NCI website:
<https://www.cancer.gov/publications/patient-education/caring-for-the-caregiver>
- **When Someone You Love is Being Treated for Cancer (NCI)**
NCI website:
<https://www.cancer.gov/publications/patient-education/when-someone-you-love-is-being-treated>
- **Ten Tips for Caregivers (Cancer Support Community)**
CSC website:
<https://www.cancersupportcommunity.org/living-cancer/living-cancer-topics/caregivers/ten-tips-caregivers>

Books from the American Cancer Society

- **American Cancer Society Complete Guide to Family Caregiving**
https://acs.bookstore.ipgbook.com/american-cancer-society-complete-guide-to-family-caregiving-products-9780944235003.php?page_id=21
- **Cancer Caregiving A to Z: An At-Home Guide for Patients and Families**
<https://acs.bookstore.ipgbook.com/cancer-caregiving-a-to-z-products-9780944235928.php>

Podcasts

- www.swedish.org/cancerpodcasts
Swedish has an extensive online cancer podcast library providing free educational podcasts and videos.

Communication tools

- **Bone Marrow and Cancer Foundation**
<https://bonemarrow.org/carelines>
Through Carelines, patients can reach out to family, friends and social networks for financial support, share updates, photos and videos, keep track of appointments and receive help from family and community members for day-to-day tasks. All contributions to Carelines are tax-deductible and do not affect a patient's medical insurance or benefits.
- **Caring Bridge**
www.CaringBridge.org
A service that provides free, private, personalized websites to make it easy for you or a family member to keep others informed.
- **Lots a Helping Hands**
www.lotsahelpinghands.com
A service that creates a free, private, online community to organize support for caregivers, friends and colleagues.
- **MyLifeLine**
<https://www.mylifeline.org/>
MyLifeLine exists to easily connect cancer patients and caregivers with friends and family in order to reduce stress, anxiety and isolation.



SWEDISH CANCER INSTITUTE

Arnold Medical Pavilion
1221 Madison St.
Seattle, WA 98104
T 1-855-XCANCER
swedish.org/cancer

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