

# going home guide for patients

## HELPING YOU TRANSITION FROM THE HOSPITAL

It's finally time to head back home from the hospital. This is an exciting point in your primary hemophagocytic lymphohistiocytosis (HLH) treatment, but it also comes with some challenges. We hope this guide will help you prepare for a smooth transition home.



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## FINDING A CAREGIVER

After you leave the hospital, the treatment team will ask you to choose a full-time caregiver. You can choose a parent, a close family member, friend, or someone you hire. This person will need to support you so you can focus on recovering. Don't be shy to communicate your needs; this person wants to do everything they can to help you.

## KEEPING A CLEAN HOME

To protect your weakened immune system, it's important that your living space is kept clean and hygienic. Since you'll need to rest to avoid straining your body, your caregiver will need to:

- Wash the floors
- Change air filters
- Keep windows and doors closed
- Remove any plants from the household
- Keep you away from a pet or animal that is sick
- Clean up after pets
- Cook according to the guidelines provided by the treatment team

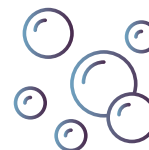
*Ask your caregiver to complete these tasks regularly to help ensure your health and safety.*

## PROTECTING YOURSELF FROM INFECTION

As you return home from the hospital, you will have to be extra careful about what you do, where you go, and who you see. It's important to avoid certain things to protect your immune system, including:

- Crowds
- People who are sick or have been exposed to infection
- People who have recently been vaccinated for chicken pox, polio, shingles, or the flu
- Gardening or digging dirt
- Smoking or being around others who smoke
- Walking, swimming, or playing in ponds or lakes
- Construction sites and remodeling projects

*If you had a transplant, you should avoid anything on this list during the first 6 months after transplant; if you are taking any medication that suppresses your immune system, you will need to avoid them for even longer.*



**If you have any questions, please speak with your treatment team.**

## WASH YOUR HANDS THOROUGHLY

Handwashing is a basic but important part of staying healthy. It is even more important for patients with primary HLH. You should wash your hands well and often before eating or preparing food, and before taking medications.



Always wash your hands after:

- Touching catheters and wounds
- Changing diapers (if you are allowed to do so)
- Going to the restroom
- Touching animals
- Touching bodily fluids or items that might have come in contact with bodily fluids (clothing, bedding, toilets, sinks, etc)
- Going outdoors or to a public setting
- Removing gloves
- Collecting or disposing of garbage (if you are allowed to do so)

## STAYING POSITIVE

This can be a stressful time for both you and your caregiver. You might feel tired and uncertain about what your recovery will be like. If you feel depressed or anxious, don't ignore or downplay these feelings. Instead, find a way to express them and relieve your stress.

Keeping your mind occupied can help. Try writing out your thoughts in a journal or blog. You can also spend time with family and friends if you follow guidelines for doing so safely.

## TALK TO SOMEONE

If you need help managing your emotions, you should speak with a family member, friend, or therapist. There are also support groups for patients to talk with others who have gone through this before.



Talk to your health care team if you have questions about how to manage your recovery at home.

The organizations at the end of this guide may be able to help you find a support group in your area. Check out their websites for more information.

# helpful information for your recovery



Visit these websites to find support groups in your area.

## **BMT InfoNet's Caring Connections Program**

[www.bmtinfonet.org](http://www.bmtinfonet.org)

## **International Myeloma Foundation**

[www.myeloma.org](http://www.myeloma.org)

## **The Leukemia & Lymphoma Society**

[www.lls.org](http://www.lls.org)



We hope this guide will help you as you go home from the hospital.