

#### A PARTNER IN YOUR PRIMARY HLH TREATMENT JOURNEY

Many professionals will provide support to you and your family during your primary hemophagocytic lymphohistiocytosis (HLH) journey. Here you will find specific information about an important member of your care team—the **social worker**.

## what is a social worker?

- A trained professional who often works in a hospital setting
- Helps patients and their families understand a particular illness
- Assists in working through the emotions of a diagnosis
- Offers counseling about decisions related to an illness

# why might I see a social worker?

Symptoms of primary HLH can be serious. People are usually admitted to the hospital for further evaluation. Also, primary HLH can be difficult to diagnose and may be mistaken for other conditions. This can feel scary and overwhelming for patients and caregivers. A **social worker** can help you get the support you might need during this time.

## what will the social worker do to get started?

Everyone's journey with primary HLH is different. Once it is diagnosed, treatment usually begins right away. The journey can be mentally, physically, and emotionally draining. It's important to know that you are not alone. The social worker will provide important assistance by:

- Having an initial information-gathering meeting with you or your child, and your family
- Helping you or your child adjust to hospital admission
- Helping you and your family understand the diagnosed illness and treatment options
- Educating on the roles of care team members
- Assisting you and your family in communicating with one another and with the care team



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#### what will the social worker do throughout the primary HLH journey?

The social worker will help you by:



Arranging for resources/funds to finance treatment



Supporting you and your family in different settings: inpatient, outpatient, home, and in the community



Coordinating patient discharge



Making sure you, your family, and caregivers have the information they need to continue care after leaving the hospital

### questions to consider asking your social worker

- What types of support resources are available?
- Are there individual counseling services available for me/my child?
- What kinds of financial programs can I access to help pay for treatment?
- How can I best communicate with members of the care team?
- Are there community support groups you recommend?
- How will care be coordinated once the hospital stay is over?
- Will I still have access to your services after leaving the hospital?

