

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 **critical care specialist**.

## what is a critical care specialist?

- **Critical care specialists** are experts in the diagnosis, treatment, and care of seriously ill and injured patients; for example, people who have been in serious accidents or who have multiple organ failure
- **Critical care specialists** treat a wide variety of health issues. These doctors usually work in the intensive care unit of a hospital

## why might I see a critical care specialist?

Primary HLH is a serious condition. Symptoms can sometimes get worse very quickly. Inflammation can have many troubling effects on the body, especially before primary HLH is diagnosed or treated. **Critical care specialists** often get involved in these early stages of primary HLH. They work to calm symptoms and keep patients alive while other doctors try to find out what is wrong.

- Primary HLH can be difficult to diagnose and can be mistaken for other conditions. This means symptoms like inflammation can get very serious before doctors find the problem
- Critical care specialists are trained to help patients with multiple organ failure, which may happen in primary HLH



## what will the critical care specialist do?



Provide emergency medical care to stabilize symptoms



Perform life-saving procedures



Give medicine to help with pain



Keep a close watch on the patient's condition



Create a detailed report for other doctors who will continue care

Once primary
HLH is diagnosed,
will I still see the
critical care
specialist?

Usually, once primary HLH is highly suspected or diagnosed, a hematologist/oncologist will take over caring for you or your child. However, primary HLH is still very dangerous. The **critical care specialist** may continue to care for you or your child if symptoms or organ function continue to get worse.

## questions to consider asking the critical care specialist

• What happens next?	
• What can be done about the inflammation?	
<ul> <li>What might happen that would need your attention?</li> </ul>	
<ul> <li>Are there any specific symptoms you are looking out for?</li> </ul>	
<ul> <li>Is there anything we can do to make sure symptoms don't get out of control again?</li> </ul>	

