Know You and Your Loved One's Rights as You Navigate HLH Care

What's most important to know and ask during this journey?

Being diagnosed with a rare and serious disease is a difficult journey for the whole family. It can be easy to forget everything to ask and what you are entitled to know as you adjust to your new normal. This bill of rights is designed to remind you and your loved ones of your right to:

1. Access safe and high-quality care, no matter your age, race, values, or beliefs.
2. Know who will be treating your loved one at all times.
3. Accompany your loved one to appointments, consultations, and hospital visits.
4. Ask to bring other support people with you and your loved one.
5. Confidentiality and privacy for you and your loved one.
6. All information and records for your loved one's care (if they are a minor or if they consent to it).
7. Ask questions as many times as you need to understand a situation.
8. Receive information in your preferred language and in a way that is easy to understand.
9. Ask for an interpreter if necessary.
10. Ask for a second opinion without consequence.
11. Request information be shared with other physicians involved in your loved one's care.
12. Ask what resources may be available to your family.
13. Ask for information about potential side effects related to any treatment.
14. To take part or decline to take part in research.
15. Information about the cost of your loved one's care.

This list is not inclusive of all your rights but is designed to help you know some of the most basic rights you and your loved one have. You may ask your health care team at any time to help you understand your rights.

HLH=hemophagocytic lymphohistiocytosis

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