

# Tips for reading "What is Lupus?" with a child

#### Using Books to Learn a New Topic

Children have amazing imaginations. They learn about their world through play, which includes books and storytelling. When presented with concrete pictures and opportunities for repetition, children are given the tools to learn, recall what they have learned, and practice what they have learned. Have you ever read the same book over and over, until one day your child tells you the story? Maybe they even use their own words and yet still are able to capture the original story.

This book is intended to help a child understand a Lupus diagnosis through visual symbols as well as having the opportunity to repeat the information (reading it) multiple times to help solidify it. We understand every medical experience is different. We wanted to provide a general introduction to the concept of a Lupus diagnosis to support in opening the door for further conversations and support with your child.

#### Who is this book for?

This book can be used to help your child understand the concept of Leukemia if they have been diagnosed, or if they know someone who has been diagnosed. This book is intended for ages 5-11 years old.

It is helpful to read this book with:

- A child who has been diagnosed with Lupus
- A sibling/s whose brother/sister has been diagnosed with Lupus, or a parent who has been diagnosed with Lupus
- Children within the community who know someone with Lupus (cousins, friends, classmates, neighbors)
- This book can be used as a tool to help a child talk about their experience of having Lupus with friends, peers, and classmates to help share about their symptoms, treatment, or what they feel is helpful for them.

#### This book is helpful to:

Introduce a new topic that is big and complex

- Give children access to information that is developmentally appropriate, both in words and illustrations.
  - When a child understands more about their world, fear and anxiety is reduced.
- Helps to open up conversation about what is happening in a child's life
- Gives the adult the opportunity to be honest about an event or new topic with the help of language and tools (a book) a child is familiar with



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### This book is helpful to:

Teach what is happening in the body, and what may happen when treating Lupus

- utilizes familiar learning tools such as visuals and allows for repetition
- understanding the body in a familiar way
- helping to explain the "why"
- Help to introduce the steps to the process which is a developmentally appropriate structure for children this age (think about how their school day is typically written at the front of the classroom so they know the routine and what to expect).

Demystify and correct misconceptions and misunderstandings

- What is a misconception? When a child encounters something new (like something medical) that they are unfamiliar with, they can create their own conclusions about what something means based on their previous knowledge and fill in the gaps with their imagination. This can sometimes lead to incorrect, sometimes scary thoughts.
- When something medical is happening within a child's environment they can hear adults talking using big words they don't have a definition for yet, and can then create their own definition.
- Thus, we encourage opportunities for adults to sit down with children to discuss these big, new, complex topics to:
  - Help them gain an appropriate understanding
  - To have one-on-one time to ask questions
  - To allow the adult to explore if the child has any understandings that are

### Development Considerations for Children Ages 5-11 years old

Preschool (4 + 5 year olds)	<ul> <li>Snapshot of developmental goals and preschoolers understand:</li> <li>Play: <ul> <li>pretend play is a prominent style for learning and practicing skills at this age, which typically involves a plan in mind for what the child wants to act out and uses a higher level of social skills by including peers and each playing specific roles</li> </ul> </li> </ul>
	<ul> <li>Learning: <ul> <li>think symbolically, learn to use words and pictures to represent objects</li> <li>begins to develop a concept of time</li> <li>tend to be egocentric which means they cannot see from the perspective of others</li> <li>their imagination broadens to include magical thinking and fantasy</li> <li>understanding the body: can identify a broader range of external body parts and can name a couple of internal body parts without the understanding of their function or really conceptualizing their existence</li> </ul> </li> </ul>



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## Development Considerations (cont.)

Preschool (4 + 5 year olds)	<ul> <li>How they relate to themselves:</li> <li>gains control of bodily functions and behaviors</li> <li>increased autonomy (doing tasks on their own)</li> <li>self-concept develops, meaning they begin to be able to identify their own thoughts and feelings</li> </ul>
	<ul> <li>Stressors from medical event or knowing others in a medical event:</li> <li>Fear of bodily injury or pain</li> <li>Loss of autonomy</li> <li>Negative thinking</li> <li>Illness viewed as punishment</li> <li>Loss of routine</li> <li>Separation from parents or familiar comfort items</li> <li>Common reactions: guilt, anger, aggression, regression</li> </ul>
School Age (5 - 11 year olds)	<ul> <li>Snapshot of developmental goals and what school-age kids understand:</li> <li>Play: <ul> <li>involvement with peers</li> <li>games with rules and the opportunity to utilize a skill they are good at</li> </ul> </li> <li>Learning: <ul> <li>increased ability to problem solve</li> <li>logical thinking begins - understanding problems and seek to solve them</li> <li>growing attention span</li> <li>concept of time increases</li> <li>imagination broadens</li> <li>understanding the body: beginning understanding of body parts working together within the body to help our bodies function</li> </ul> </li> <li>How they relate to themselves: <ul> <li>experiences more independent and autonomous self-care</li> <li>self-esteem and self-identity really begin to take shape, they identify more with what skills they have and how these skills contribute to the needs and interests of the group</li> </ul> </li> </ul>
	<ul> <li>Stressors from medical event or knowing others in a medical event:</li> <li>Feelings of loss of bodily control or functioning</li> <li>Feelings of forced dependence on caregivers or others</li> <li>Separation issues related to disruption in daily living, school, and peers</li> <li>Fear of pain, bodily injury, mutilation</li> <li>Fear of loss of control, loss of love, loss of respect</li> <li>Regression in cognitive skills</li> <li>Disruption in self-esteem and self-identity can cause stress</li> <li>Can view illness as punishment</li> </ul>