

Overcoming Psycho/Social Challenges Associated with Leukodystrophy and Chronic Illness

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Bio

Licensed Clinical Social Worker

Kennedy Krieger Institute since 2012

Moser Center for Leukodystrophies since 2015; as well as other medical clinics

Worked with children and adolescents with chronic illness since 2010

Objectives

- ▶ Coping and adjusting with chronic neurological disease
 - ▶ As the patient
 - ▶ As the family
- ▶ Overcoming social challenges
- ▶ Transitions
- ▶ Supports and resources for the family

How Chronic Illness Affects the Family

Patient

- ▶ Frequent medical appointments
- ▶ Increased dependence
- ▶ Loss of innocence
- ▶ Connection to peer group
- ▶ Confusion, anxiety, anger and sadness
- ▶ Sense of isolation

Family

- ▶ Frequent medical appointments
- ▶ Change in routine
- ▶ Demands on the caregivers
- ▶ Feelings of anger, guilt and sadness
- ▶ Sense of isolation
- ▶ Grief and loss

Coping and Adjusting

Patient

- ▶ Parent support
- ▶ Appropriate amount of knowledge about the disease
- ▶ “Normalcy”
- ▶ Enjoyment

Family

- ▶ Knowledge is power - reliable information
- ▶ Family and community supports
- ▶ SELF-CARE



How to talk to the child/adolescent

- ▶ Find out what they know about the situation
- ▶ Let them lead the conversation and observe their reactions
- ▶ Ask open ended questions
- ▶ Provide information that is age and developmentally appropriate
- ▶ Ask them how they are feeling about the information given to them
- ▶ Encourage them to ask again when they have more questions
- ▶ Provide information on what to expect; treatment, therapies, etc.
- ▶ Reminders that it is not their fault

How to help the child/adolescent

- ▶ Caregiver affect management
- ▶ Open and honesty - age appropriate language and information
- ▶ Focus on strengths, quality of life, relationships
- ▶ Affect expression and understanding
- ▶ Assessing for change in mood
- ▶ Stick to normal routines and rules - avoid overindulgence

Sibling Support

- ▶ Provide age and developmentally appropriate information about the sibling's disease and symptoms
- ▶ Acknowledge their feelings
- ▶ Quality time together - being present in the moment
- ▶ Find ways for the sibling to be involved, if s/he wants to help
- ▶ Keep routines as consistent as possible
- ▶ Support groups - Sibshops

Social Challenges

- ▶ Disrupted routine
- ▶ Difficulty connecting to peers
- ▶ Limitations due to risk of health concerns
- ▶ Anxiety and depression



Transitions

- ▶ Appropriate planning
- ▶ Needed support services and/or accommodations
- ▶ Pediatric to adult medical care
- ▶ Employment
- ▶ Managing change in mood

Resources

Sibling Support Project - <https://www.siblingsupport.org/>

Sibling Leadership Network - <http://siblingleadership.org/>

KidsHealth - <https://kidshealth.org/>

PBS Parents - <http://www.pbs.org/parents/talkingwithkids/health/>

The Brooks Coleman White Foundation - <https://www.bcwfoundation.org/>

The Myelin Project - <https://www.myelin.org/>