Overcoming Psycho/Social Challenges Associated with Leukodystrophy and Chronic Illness

Kiley Morgart, LCSW-C
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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/