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Psychosocial Factors Affecting Children and Families Living with Chronic Illness

This webinar will start shortly. It will be recorded and the slides will be available at www.dpcedcenter.org

Next webinar: June 27th at 2:00 pm Eastern

Vocational Rehabilitation Works for You and Your Quality of Life!

Reminders

- All phone lines are muted
- **Unmute: #6** to ask questions at the end of the presentation
- **Mute: *6** after your question
- Or, ask questions through the Chat Box
- You will receive the link to the **recording, slides, & handouts** by email
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Psychosocial Factors Affecting Children and Families Living with CKD and Other Chronic Conditions

A presentation for the Dialysis Patient Citizens community

By Amy Walters, PhD
Clinical Health Psychologist
Boise, Idaho

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Objectives

Identify the psycho-social impact of chronic conditions on children

Describe common developmental tasks and the impact on chronic conditions

Discuss the impact of chronic conditions on the family

Identify key areas of concern as reported by families

Discuss ways to support children, adolescents and families coping with chronic conditions

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Disclosures

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My Journey, My Lens, My Story

Brother seizures - - - - - - - Premature twins - - - D1: Diabetes - - - Chronic Migraine - - - POTS - - - D2 Migraine and GI

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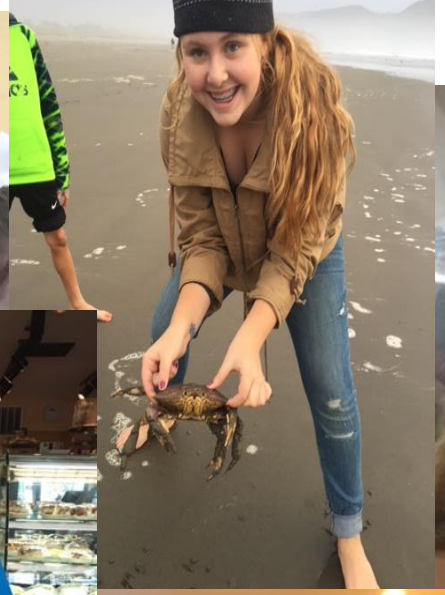
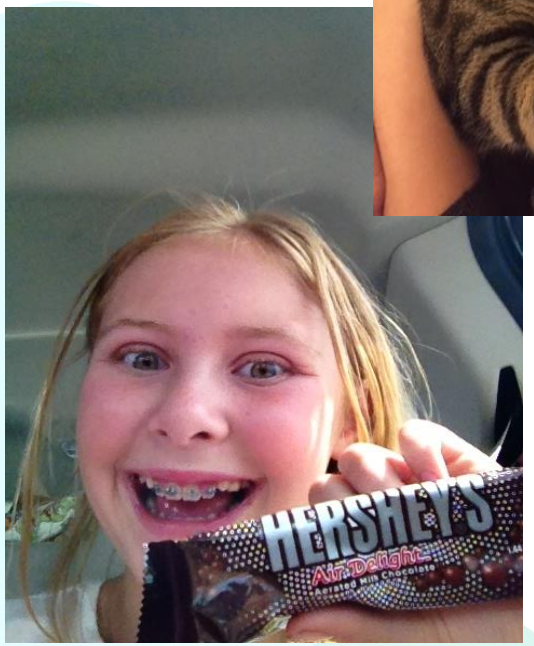
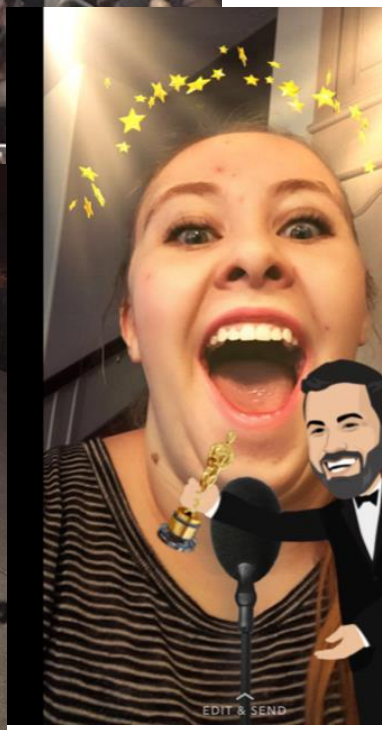
Meet Sophie







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Children and Chronic Conditions

Approximately 20 - 30% of children are affected by a chronic health condition (one third of all Americans) – CDC data

Rates have increased over last decade

- Environmental factors
- Advances in medical technology – mortality has decreased, but chronic illness has increased

Definition:

"conditions that threaten health & development and require special medical treatments and services"

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Chronic Health Conditions

May last throughout a person's life, although the frequency and severity of symptoms can change

Examples of chronic health conditions in children:

- Asthma
- Allergies
- Cancer
- CKD
- Cystic fibrosis
- Diabetes
- HIV
- Mental health (autism, bipolar, depression)
- Seizures

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Psychological Impact of Chronic Conditions

Psychosocial factors are common and prominent treatment issues

Many patients report:

- Lifelong issues with depression, anxiety, social isolation, and feelings of hopeless, helplessness, and ineffectiveness
- Daily struggles trying to balance the demands of their illness with the social, emotional, family, and occupational demands of their lives
- Feeling as if their chronic conditions rules their lives and defines them as a person.
- Negative impact on quality of life

Adherence is a significant issue with emotional and behavioral underpinnings

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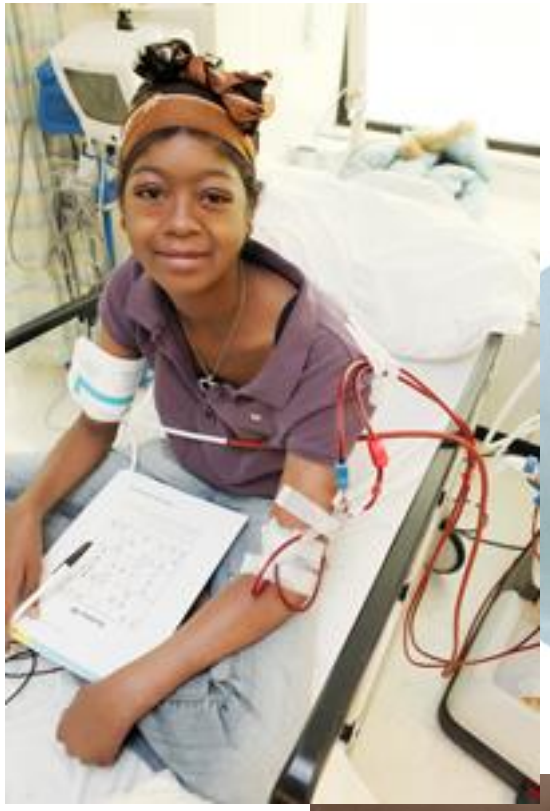
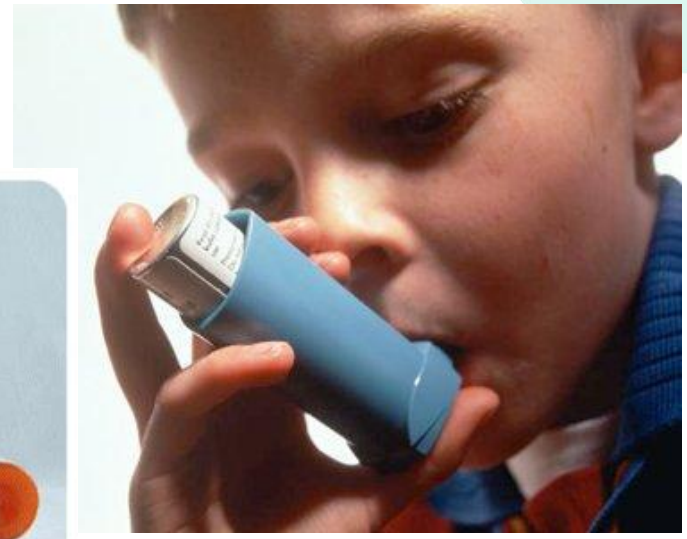
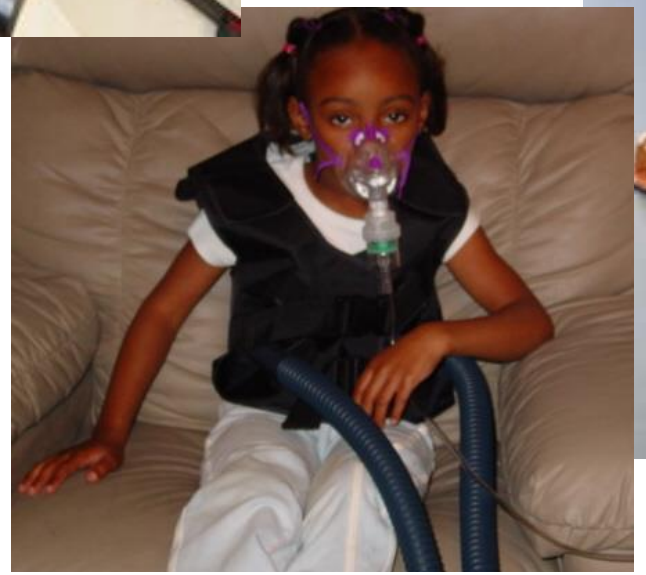
Why do psychosocial issues occur?

- Take your medicine
- Do your treatment
- It's time to go to the doctor - again
- What did you eat?
- How much did you eat?
- You need to eat more
- You need to eat less
- No you can't have that!
- You can't do that
- I know other kids do it but they don't have (fill in the blank)







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Adherence

What is Adherence? *How precisely we follow our medical regimen*

- **Adherence is a significant issue with most chronic conditions**

Most chronic conditions have adherence rates below 50%

Self report of adherence has poor accuracy across conditions

- We over-report success and under-report issues
- The proof is in the data

Adherence declines from early childhood to adolescence

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Factors Contributing to Adherence

Negative emotions are part of the package

- Feelings of frustration, anger, worry, guilt, failure, sadness, helplessness and hopelessness are common
- Negative emotions contribute to burnout and avoidance

Common factors: forgetting, opposition/refusal, time, complexity and intensity of medical routine

Psychological Impact of Chronic Health Conditions

Anxiety and depression are common

- *these are normal reactions (for parents and children) to an abnormal circumstance*

- *early screening is critical and should be routine*

Both issues impact adherence differently

- Depression is linear (greater depression=poorer adherence)
- Anxiety is variable (moderate is good, too little or too much is problematic)

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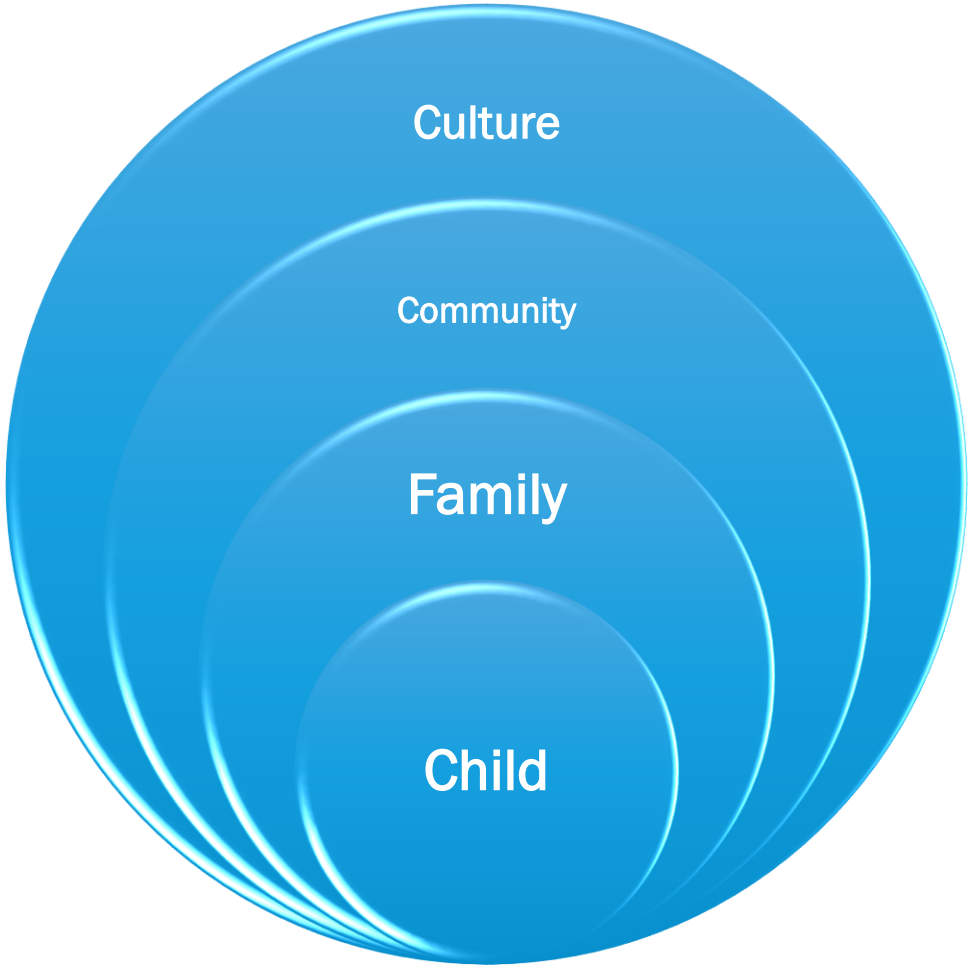
Health in Context



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Psychosocial Issues in Context

Child first - not disease

- Think about typical development for the age
- Child with diabetes – not a diabetic – NOT THEIR IDENTITY

Part of a system

- Family
- Peers
- School /Community

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Chronic Conditions in Context

Typical developmental tasks

Common issues for the age group

Developmentally appropriate ways to support the child

Early Childhood

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Early Childhood - Development

Early Childhood is a time of rapid growth and development

Major developmental tasks: independence and mastery of environment

Important to account for developmental tasks and work into medical care regimen

Chronic conditions diagnosed in infants and toddlers have a profound effect on the parent-child relationship

Common Early Childhood Issues

- Testing limits and control
- Refusal to cooperate with medical regimen
- Conflict over food
- Parent stress

Support- Early Childhood

- Choices
- Time window for compliance
- Assistance as interested
- Work around food preferences
- Provide toys simulate medical care
- Support and accommodate normal developmental tasks
- Parent support and normalizing emotions is key to treatment

Elementary

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Development- Elementary

- *Major developmental tasks*:
- Separation from parents
- Skill development
- School transition and reliance on others outside of family
- Developing close friendships
- Comparing self with others-identity

Common Elementary Issues

- School transition
- Social Events (parties, sleep-overs, activities)
- Self-esteem
- Peer reaction
- Responsibility for self-care

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Support - Elementary

- Increased involvement in care -self
- Share information about disease with friends
- Written plan to facilitate care by others
- Fully participate in age appropriate activities with *as few restrictions* as possible
- Flexibility in regimen to support activities and peer interactions – ***child first: make the disease fit the child, not vice versa***

Adolescence

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Development - Adolescents

Major tasks:

- separation and independence
- development of identity
- friends become primary source of support and influence
- limit testing, impulse control, and planning issues
- increased responsibility for self care

Adolescent Issues

- Parent conflict
- Limit testing
- Parent conflict
- Here & now attitude – ignore long term consequences
- Parent conflict
- Peer influence
- Substance use
- Poor & inconsistent eating & sleeping habits
- Poor self management
- Depression and anxiety

Support – Adolescents

- Knowledge and skills are necessary, but not sufficient
- Allow more control of care (but stay involved)
- Help build support/safety net
- Train friends in health care routine
- Develop clear expectations and use behavior contracting
- Communicate with acceptance, respect and honesty
- Help build self-efficacy and positive health beliefs

Adjust Focus to Health and Wellbeing

What does the child *want?*

What does the child *need?*

How can we provide appropriate *support ?*

How can we *accommodate*?

How can we *help rather than hinder*?

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Support for All Ages

Strong research for the value of ***psychological treatments***

- Include a psychologist on the treatment team

- Obtain behavioral consultation shortly after diagnosis and as needed for follow up- different issues arise at different stages of development
- Behavior modification strategies, open communication and family based interventions enhance management

- Conduct routine screening for psychosocial issues

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Key Concepts for Support

Empowerment & Self efficacy – promote it

Control – as much as possible; avoid power struggles

Energy & resources – often maxed out

Support – part of a team

Avoid lectures and scare tactics – have enough fear

Positive behavioral supports – reinforce + behaviors

Key Concepts for Support

Normalization & include

Child first

Grief – child and parent; may recur at different life phases

Communication - with child, parent and medical staff

Adaptability – psychological flexibility

Hope - “Can Do” approach

Skills training – targeted areas as needed

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How Do Chronic Conditions Impact the Family?

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Meet the family

David – good cop & insurance provider

Sydney – twin/admin assistant caretaker, social coordinator

Grandma Lolo -childcare substitute mother, sounding board for mom

Jack -distractor, professional pester and comic relief

Grandma Karen - Diabetes knowledge, on-call support, taxi driver

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“ The strains of childhood chronic illness on the family are unlimited…No list of potential stressors can do justice to its perspective impact.”

Barakat and Kazak (1999) Family Issues in Cognitive Aspects of Chronic Illness in Children, pg 333.

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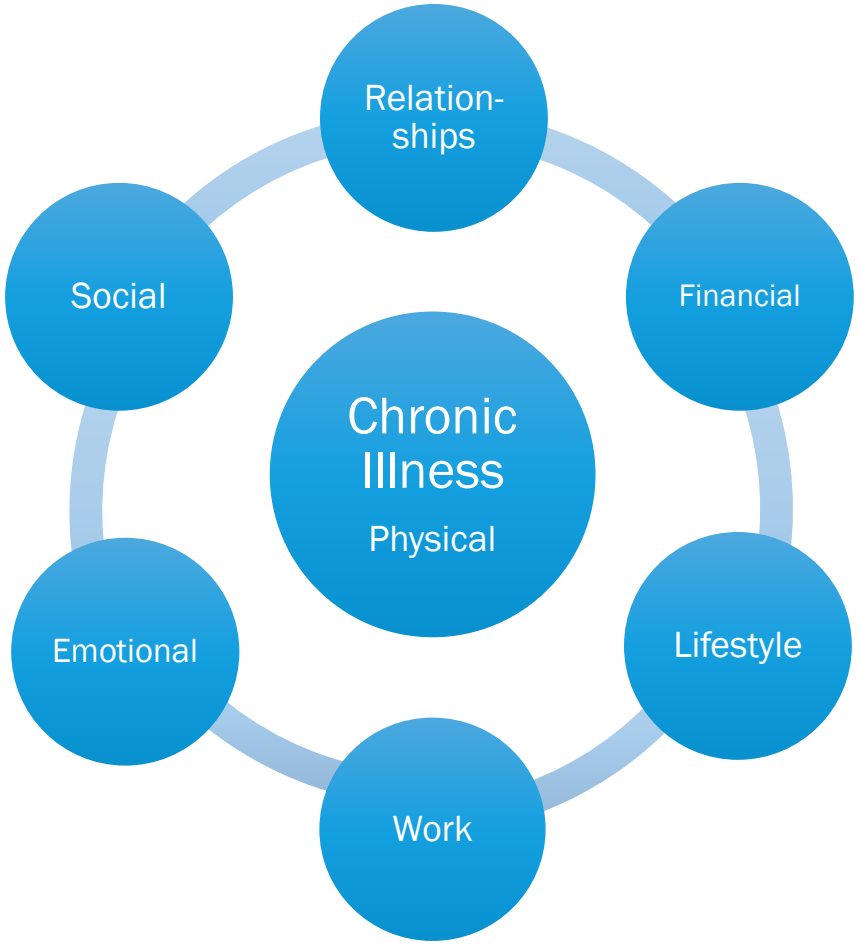
Areas of Impact



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Family Impact of Chronic Illness

Relationship is bi-directional

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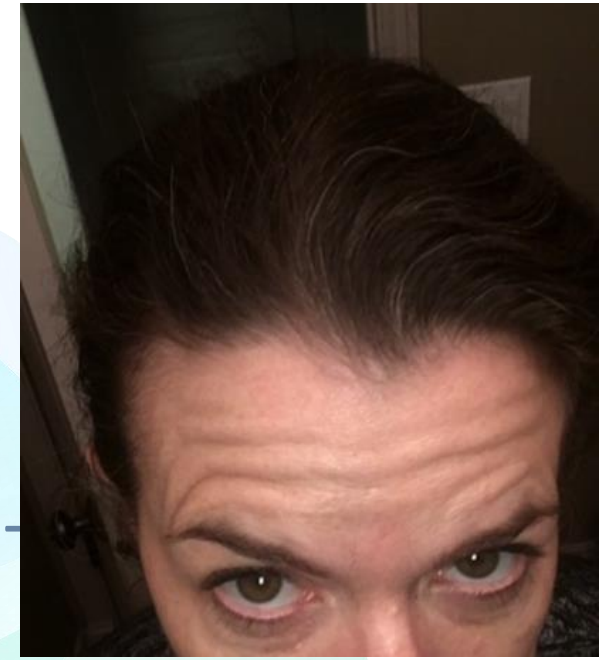
“Families of children with chronic illnesses often live in a state of increased vigilance, amplified anxiety and emotional exhaustion”



(Kratz, Uding, Trahms, Villareale, & Kieckhefer, 2009).

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Family Functioning

The good news: Disease ≠ Family pathology

- Many studies report no differences in family functioning between families with and without a chronically ill child

- Protective factors for adjustment: **cohesion**, **expressiveness**, **control** and **low conflict** (Barakat and Kazak; 1999)

- ***Parental stress***, ***functioning*** *and* ***adjustment*** are better predictors of child adjustment than disease and disability parameters (Lavigne and Faier-Routman ; 1993)

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Parent Adjustment

What factors best predict successful parent adjustment?

- Stress
- Social support
- Sense of Competence
- Coping strategies

- Disease parameters and illness severity are not strong predictors, but stress is higher with more demands of the illness

Barakat and Kazak (1999) Family Issues in Cognitive Aspects of Chronic Illness in Children

Family Issues by Developmental Level

Early Childhood

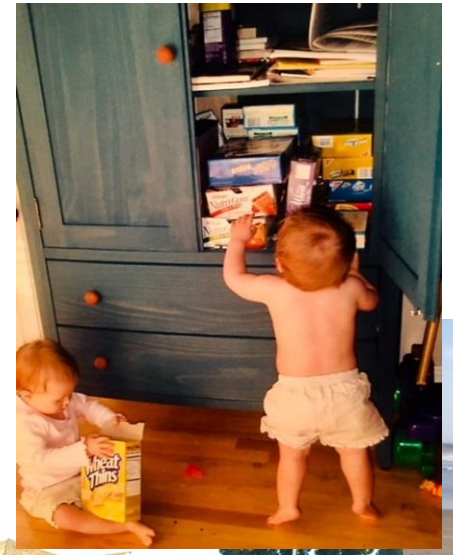
- Managing parent stress
- Sharing burden of care

Childhood

- Helping child understand the illness is not their fault
- Addressing sibling issues
- Educating other care providers

Adolescence

- Re-negotiating roles and expectations
- Minimizing parent conflict
- Managing common teen issues + illness
- Preparing to transition to independence



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Impact on Sibling Relationship

“Negative impact of chronic disease on the emotional status of the patient's siblings is well recognized” Stewart et al 1992

- Feel "neglected"
- Jealous of the attention
- Guilty for health and feelings

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Additional Family Issues

- Marital distress and couple time
- Self-care of caregivers
- Respite and impact on extended family
- Split parent homes

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Supporting Care Providers

Parent self care is critical to avoid burnout

Remember to go EASY on yourself

- Expectations
- Adaptations
- Support
- You (self-care)

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Circles of Self Care

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Take Home Points

Consider developmental levels and common issues at each level when problem solving

Psychosocial issues are part of the “chronic disease package”

Include behavioral health professionals on treatment teams

Child first

- Not their identity
- Normalize
- Encourage age-appropriate independence
- Make the disease fit the child, not vise-versa

Promote wellness and normal development

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Remember the end goal: A happy, healthy child and family

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Questions?

Chat box or unmute phone - #6

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