

# Coping strategies for managing a child with complex medical needs

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# Congenital hyperinsulinism

- Pediatric illness
- Rare disease
- Chronic illness



# Pediatric illness

- Children are developing:
  - They are changing and growing
- Children are vulnerable:
  - They are not able to speak or express themselves
  - They are not aware of what they need
  - They can not take care of themselves
- Parents have to take care of the child:
  - The parents' role versus the carers' role
  - They must make decisions on medical or surgical treatment for their child
  - Sometimes have to face a lethal or disabling condition

THE DISEASE NOT ONLY AFFECTS THE INDIVIDUAL, IT AFFECTS THE WHOLE FAMILY

Rare diseases in peadriatics. D González-Lamuño, M García Fuentes. An. Sist. Sanit. Navar. 2008; 31 (Supl. 2) 21:29

# Rare disease

- It is an uncommon and little is known about it
- There are fewer resources and they are less specialized:
  - The care for parents is more complicated
  - The life for these children is more difficult
    - Growing
    - Hospitals
    - Treatment
    - Play
    - Nursery-school/School
    - Sport
    - Social relationships
- Stigma → Social isolation

THE IMPORTANCE OF THE PARENTS' ASSOCIATIONS IN THESE LITTLE KNOWN DISEASE CAN BE A SUPPORT FOR THE PARENTS AND THE CHILDREN

Rare diseases in peadriatics. D Gonazález-Lamuño, M García Fuentes. An. Sist. Sanit. Navar. 2008; 31 (Supl. 2) 21:29

# Chronic illness

- Permanent or residual disability
- Irreversible pathological changes
- It requires continuous monitoring, observation, care and rehabilitation
- Families need to adapt to chronic disease:
  - Diagnosis
  - Day after day
  - Long term consequences
- Parents of children with chronic disease:
  - Are the most affected with the diagnosis
  - They can never take a break
  - Could be overburdened with management and caring of the child

CHILD AND PARENTS HAVE TO MAKE LONG TERM CHANGES IN THEIR LIVES

Family and chronic paediatric illness. Grau C, Fernández M. An. Sist. Sanit. Navar. 2010; 33 (2): 203-212



**MEDICAL TEAM**



- Carers
- Expectations
- Feelings
- Family ties



- Give information
- Support



**FAMILY**

Body and life  
impact



**PATIENT**

# Grieving for the healthy child

- Kübler-Ross Model

Five stages of grief:

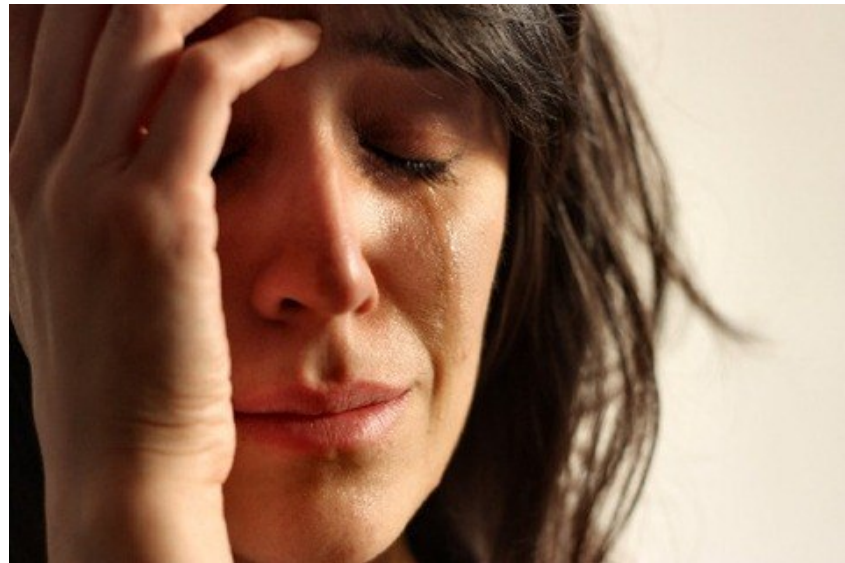
- Denial
- Anger
- Bargaining
- Depression
- Acceptance



Course Childhood adversities. Marta Albert. Psychiatry and Psychology department, Hospital Sant Joan de Déu, Barcelona

# Parents

- May exhibit emotional and psychological symptoms such as:
  - Sadness
  - Guilt
  - Anger
  - Feeling of powerlessness
  - Anxiety
  - Fear
  - Insecurity
  - Loss of self-esteem
  - Somatic symptoms: pain, feeling unwell...



Stress related to care: the impact of childhood cancer on the lives of parents. DF Sants Alves et al. Rev Latino-Am Enfermagem. 2013 Jan-Feb; 21(1):365-62



# Parents

- These symptoms can interfere:
  - Parents level of understanding → Adherence to treatment
  - Negatively influence the behavior of the child
  - Affect the prognosis
- And...
  - Their health and lives!



## PARENTS HAVE A HIGHER RISK OF DEVELOPING MENTAL ILLNESS

Stress related to care: the impact of childhood cancer on the lives of parents. DF Sants Alves et al. Rev Latino-Am Enfermagem. 2013 Jan-Feb; 21(1):365-62

# Warning signs!!

- If symptoms continue for longer than six months
- Greater discomfort than expected
- Significant impairment to occupational activity
- Feeling guilt or worthlessness
- Thoughts of death
- Weight loss
- Insomnia



Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition, DSM-5. American Psychiatric Association. 2013

# Resilience

- A set of social and personal processes that enables people to adapt well physically and psychologically, despite adversity
- Family resilience (Walsh, 1996):
  - Processes of adaptation and adjustment of family to demands of illness
  - It is essential to maintain a good quality of life for children and their family
  - A family with resilience is able to mobilize its resources and use support systems
  - It depends on:
    - The sick child: reactions, emotions, symptoms...
    - Disease: stage, course, severity...
    - Family: culture, organization, communication...
    - Contexts: employment, health...
- Professionals can help families develop resilience

Building resilience in families with pediatric chronic diseases. Grau Rubio, C. Revista española de discapacidad. 2013, 1 (1), 195-212.

# Resilience

- Multi-dimensional intervention model:
  - Centered on the family's characteristics and specific needs
  - Knowledge of the disease and troubleshooting
  - The support available in their environment
  - The development of capacities and resilience
- Multi-disciplinary team:
  - Doctor
  - Nurse
  - Social Worker
  - Mental health professional:
    - Psychological therapy: individual/group
    - Drugs

Care burden in caregivers of children with chronic disease. Barrer L, Sánchez B, Carrillo G. Revista Cubana de Enfermería, 2013; 29 (1): 39-47

# Strategies for parents

- Learn about the illness
- Talk about questions and concerns
- Seek support from family, friends, other affected families, professionals...
- Accept offers of help by friends and family
- Recognize psychological or behavioral changes
- Take care of yourself: eat well, sport, sleep...
- Breathing and relaxation techniques, yoga
- If possible go to work
- Take each day one day at a time
- Don't compare your life to others
- Don't try to be a perfect person

*Guía para tratar la diabetes de su hijo. Endocrinology department, Hospital Sant Joan Déu, Barcelona*

# Strategies for children

- If it's possible maintain daily routines
- Teach children about the illness
- Encourage children to participate in their care and treatment
- Talk with the child: use simple language
  - Reassure children, ensure they do not feel guilty
  - Explain that you understand how difficult the situation can be
- Recognize psychological or behavioral changes
- Do not judge their feelings
- Relaxation techniques

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# Relaxation session

- Deep breathing:
  - Sit comfortably
  - Put one hand on your stomach
  - Close your eyes
  - Breath in through the nose (5s)
  - Hold the breath (5s)
  - Breath out through the nose or mouth (10s)
  - Repeat five times



*Manual de entrenamiento en respiración. Universidad de Barcelona. Facultad de psicología. E García-Grau, A Fuster i A Bados*



**THANK YOU FOR YOUR ATTENTION!!!**