

Coping with Chronic Illness in the Family

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Unlike acute illness that may be serious but can be diagnosed, treated and resolved, chronic illness (e.g., Diabetes, Cystic Fibrosis, Multiple Sclerosis...) continues long after the diagnosis is made. Typically, the course of a chronic illness, absent a cure, involves periods of active follow up, treatment, monitoring and occasional hospitalizations followed by a return to relatively normal life. Rothmund-Thomson Syndrome (RTS), as well as, other rare genetic disorders share this similarity with other chronic illnesses. Learning to live with RTS can be especially challenging given that it is a rare disorder that is poorly understood by the public and the medical community. Furthermore, the effects of a chronic illness like RTS are not limited to just the patient. Every member of the family is affected in their own unique way. Some of the ways that chronic illness can influence family life include:

- Daily routines may change because of the limitations of the ill member and the demands of treatment may require that others to be more available.
- Families may need to share care giving responsibilities; this helps all members feel they are contributing to a loved one's welfare and it also protects any single member from caregiver fatigue.
- Family members may experience strong emotions, such as guilt, anger, sadness, fear, anxiety and depressed mood. These are normal reactions to stress. It is useful to talk about these emotions within the family.

- The ill member may need to find ways to be as independent as possible, given the limitations that the illness causes.
- Genetic conditions have powerful effects on families including; a genetic diagnosis for one family member may mean other biological relative are at risk members, concern about difficult treatment options, lack of cure for the condition, the chance that additional offspring's will inherit the condition, and prenatal and newborn testing decisions.
- Despite the demands of the illness, families may need to work hard to maintain a sense of "normal" life. This can benefit the ill member, as well; it may help him or her to integrate into family life more and may reduce the ill member's sense of guilt regarding the demands the illness places on the family as a whole.

Each family member will be affected differently by these changes. The challenges that each family member faces are influenced by various psychosocial factors, personality as well as their role in the family. For example, parents are the administrators in charge of the family's day-to-day life. As such, they are responsible for making decisions regarding the many issues and concerns that impact the family. They can easily become overwhelmed by all the responsibilities they shoulder, especially when they also work outside the home. With the added accountability of caring for a child with a chronic illness, they are at risk of parenting stress. As parents, caring for your child with a with chronic health condition may involve dealing with many things including:

- Trying to adjust to the new reality that has been thrust upon you.

- Confronting difficult family-planning decisions due to chance of inheriting the condition, and hard choices regarding prenatal testing and termination of pregnancy
- Experiencing guilt due to the hereditary nature of child's genetic condition
- Understanding and adjusting to any new limitations
- Talking to people who are supportive, including family, friends, your child's healthcare team and support groups
- Educating yourself about your child's condition and the care your child requires
- Getting organized so that you can easily keep track of your child's needs
- Building a solid relationship with your child's health care team that enables you to feel comfortable asking questions and to trust that the team has your child's best interests in mind.
- Informing others (family, friends, caregivers, school) about your child's situation so they are able to assist you in caring properly for your child
- Getting help while your child is in the hospital so that your other children are cared for and practical needs are taken care of
- Putting systems in place at home, at school and other places that make it easier to care for your child and manage this new situation
- Finding ways to relieve stress that naturally come occurs when adjusting to any new situation

Here are some approaches that might help you manage stress while caring for your child with a chronic condition:

- **Talk to others** – Talking to someone you trust and rely on is one of the best ways to deal with your feelings. This can be a family member, friend, support group, social worker or psychologist or other helping professionals.
- **Connect with other affected families** – You are not alone. While RTS is a very rare disorder, you can connect with other RTS families via the RTS website (rtsplace.org). In addition, you can participate in the RTS online support group forum, attend the sharing and caring conferences held annually in different states and cities. These conferences provide updates on RTS related medical and research developments and serves as an opportunity for connecting with other families to share advice and support one another.
- **Focus on your relational wellbeing** – Take care of yourself and your partner. Every instinct will tell you to put your child first, but it is vital to take care of yourself physically, psychologically and emotionally. Men and women often report coming to terms with the diagnosis of a genetic disorder in different ways – understanding different responses can help one and another be more considerate to each other and avoiding blame, guilt, anger and a host of other emotions that can place stress on the relationship.
- **Share the responsibilities** – Whenever possible it is helpful if both parents are involved with health care routines. Working together to care for a child can help prevent “burnout” by sharing the load. Giving each other time away from care duties can provide much needed breaks. It can also help to plan time together, apart child or children, just as you did before. Lean on family or friends for support and help in managing the many aspects of caring for a child with a chronic condition.

- **Consider the use of respite care** – Respite care is a community health service that can provide temporary relief from the physical and emotional demands involved in caring for a child with a chronic health condition. It allows parents and caregivers time for themselves to recharge.
- **Maintain good physical health** – Healthy eating, sufficient sleep, regular exercise and opportunities to engage in activities that help you relax are important factors in maintaining your physical and emotional well-being.
- **Take time for yourself** – As difficult as it may seem, try to make some time for yourself and your spouse or partner each week to reduce your stress. Caring for a child with a complex health condition may seem to take up every minute of every day. You might feel as if you have no time for the things you use to like to do: read a book, take a walk or go to a movie. Taking this time can really help to refresh yourself so that you can continue caring for your child to the best of your ability.

Parents are not the only ones who must adjust to a child's illness. Life changes for the whole family. Parents have to pay extra attention to a child with chronic illness and siblings may often feel neglected. They might also have difficulty learning to live with the stresses of having a sibling with a chronic health problem. Some of the ways that siblings might feel, based on age and developmental status, include the following:

- Guilt that they are not sick (Why him and not me?)
- Wonder whether they might have caused their sibling's illness

- Anxious about becoming sick themselves given the hereditary nature of genetic disorders
- Jealous and wish they could become the center of the family's attention
- Angry if they are asked to assume more household chores than their sibling with chronic health problems
- Guilty when they resent the additional responsibility, they are tasked with
- Embarrassed or angry when strangers stare at their brother or sister in a wheelchair, or when other children tease their sibling because he or she looks different

Knowing that siblings have their own set of challenges, it can be helpful for parents to be mindful of some of their parenting behavior. For example, in attending to the needs of your child with chronic illness, you may be neglecting or creating unfair expectations for your other children. At times, siblings may feel invisible unless they demand attention. However, siblings can learn to participate in the family and feel pride and love in helping their brother or sister with his or her health problem. The presence of a family member with chronic illness provides opportunities for increased empathy, responsibility, adaptability, problem solving and creativity. Furthermore, parents can help by incorporating some of the following the following tactics:

- Try to establish some balance between the needs of your child with chronic health problem and those of your other children
- Spending some time with each child individually may help
- Develop a special relationship with each of your children

- Keep in mind that siblings need to have honest information about their sibling's illness and to have their questions listened to and answered
- Consider getting individual, family or group counseling if attempts to resolve difficult family dynamics have been unsuccessful

How might your child be affected by their chronic illness? The psychosocial impact of a genetic diagnosis on a child and his or her family is difficult to predict given that every person and family is different. A genetic diagnosis can provide a great benefit to the patient and family when the condition is rare, like RTS. Knowing the name and cause of the condition can help make sense of the situation. Diagnoses can lead to improved treatment options and access to support services. A genetic diagnosis may lead to negative reactions, too. A common response is that the science of genetics is confusing and frustrating. Patients identified with a genetic diagnosis may consider themselves at fault or “broken” or interpret their diagnosis as leading to something they cannot handle. A genetic diagnosis can lead to concerns about stigmatization.

Children with chronic illness are more likely than other children to experience frequent doctor and hospital visits. Some of the medical procedures they undergo can, in fact, be frightening or painful. Hospital stays can also be frightening and lonely. They will likely feel “different” than other children. Their activities may be limited, and, in many cases, their families must change how they live to accommodate the child.

As your child grows up with chronic illness, they will need to discover a balance between dependence and independence. Chronic illness may limit a child's activities a lot or a little, and the limitations may come and go. Consider these ideas for fostering independence:

- Encourage your child to participate in as many family jobs and activities as possible
- Ensure that your child can maintain friendships with peers
- Identify activities with your healthcare providers that are suitable for your child's condition and encourage your child to experience everything in life they physically can. The more normal activities they participate in, the less different they will feel from their peers
- Allow for mistakes and messes. They help to model for your child how to cope when things don't work out as expected
- Provide consistent, appropriate discipline to all your children. It is very important to teach your child with chronic condition the same important lessons in life. This approach will also help your child feel normal.
- Assist your child in getting a variety of school-based support services based on identified academic, social or physical needs, as well as, psychological help should they be struggling with anxiety and/or depression.

While families can certainly be challenged by the many demands of raising a child with a rare chronic condition like RTS, families can also thrive as they embrace and care for a child with a chronic illness. A child with health problems may bring parents and other family members closer. Families –

especially those who communicate openly – may be strengthened by experiences associated with managing their child’s health condition. In many cases, the family’s management of a child’s chronic condition may provide them with a sense of cohesiveness, mission, mastery, and pride which builds the resiliency of the family.

Selected References:

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