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The Stress of Special Needs

Welcome to the Science of Parenting, a podcast dedicated to sharing scientific information with parents. I'm Lori Hayungs, Human Sciences Specialist Family Life Program for Iowa State University Extension and Outreach.

Most parents would say that the job of parenting is stressful, and those who parent a child with special health and behavioral needs are likely to have even more challenges. The usual demands of parenting are multiplied for parents and caregivers of children with special needs. The Center for Disease Control reports that 15 percent of U.S. families have a chronically ill child with special health needs.

Marsha Mailick Seltzer, Director at the University of Wisconsin-Madison's Waisman Center followed the daily experiences of mothers with adolescent and adult children with autism over a period of eight days. The study found that on four of the days, the levels of cortisol, a stress hormone were higher than normal. The stress profile was similar to that of combat soldiers and others who experience constant psychological stress.

The extra demands cause stress that affects the whole family. Researchers at Case Western Reserve University have found several factors in the care of the child that most add to the challenges of parenting. The study concluded that the demands of care created greater stress than the length or severity of the child's illness. Melissa Cousino, M.D. and Rebecca Hazen with the Department of Pediatrics at Case Western identified common stress triggers which included--extra health care needs such as multiple doctor and therapy appointments, medical treatments, hospitalizations, and school issues. Parenting can become overwhelming while the parent also attempts to integrate the ill child's needs into the family routine.

Three challenges that may impact parents include: guilt, isolation and grief. *Guilt* over the ability to protect the child, and the loss of attention towards other children, spouse and potentially aging parents. The resentment of those with a "normal" child can be burdensome. Many parents experience *isolation*. It's not uncommon to experience feeling like an outsider among parents of children who are developing typically. Perhaps the parent even experiences criticism and judgement from other's who simply do not understand the child's condition. *Grief* over the hopes and dreams that have changed and the recurring reminders of what your child might be missing out on can lead to chronic sorrow and grief.

The list of challenges that parents and caregivers face is long. The challenges include—learning about the disability, finding and researching treatments and resources, coping with the emotional and physical challenges of caring, coordination of healthcare treatments, advocating and paying for necessary services---are just a few of the challenges and worries!

No wonder parents of children with special needs are often exhausted and frequently experience depression. The need for self-care is imperative and ongoing. The potential to deplete time and resource reserves is great. Parents must be mindful to attend to their own needs. It is important for parents to seek strategies to reduce parenting stress: Being open to assistance, share parenting and treatment responsibilities, and well as being open to talking to your healthcare provider.

Join us this month on the Science of Parenting as we discuss the challenges of parenting when health and behavior needs are a challenge. We will look at self-care tips that many parents find useful. We will

share resources available that can help parent's cope. We will discuss ways that the family can support each other as well as reach when and how to reach out for assistance. We will explore resources available through the cooperative extension system that can help you reduce stress. . As always, we look forward to hearing from you and how you have benefited from a growing experience.