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## **“Family Care” by Colleen Kintner, ULF Board of Directors & Family Counselor**

Our leukodystrophy journey began when my stepdaughter was diagnosed with Metachromatic Leukodystrophy at the age of 6. I married her father when she was 4. She was our healthy, precocious little person. She was the flower girl at our wedding. Custody was shared with her mother. When Kristy was diagnosed, we all initially reacted with shock and disbelief. When the shock and disbelief diminished, we all proceeded differently.

We all began our leukodystrophy journey at different points of life and different skills to deal with this diagnosis. Care for all the family and relationships within the family are essential. There are some aspects of care that I believe we need to consider.

**Communication;** open, respectful, honest communication is necessary. Many of us have some challenges communicating our thoughts, feelings, and needs routinely, so when under stress, this aspect of care can be even more challenging.

**Listening** is a core aspect of communication. This can be difficult when others are verbalizing ideas and feelings different than ours. Reactions to news such as a diagnosis of a major illness can vary significantly. So, let’s consider this question, are reactions right or wrong, or simply different? Simply different.

Communicating takes time and at many points in our lives, time is looked at as a luxury. **Making time**, even a few moments, is essential. Making time means prioritizing conversation in spite of other life challenges. It also means prioritizing all relationships, other children, the couple, and us as an individual.

**Seeking assistance** and knowledge of the illness, potential treatment and care from others who have walked a similar journey before you is very helpful. The United Leukodystrophy Foundation is an excellent resource to answer questions and help you go in the right direction. Not all of us have the same capacity to understand information given or even to know what assistance we may need. That is not because we are not intelligent, it is simply because we do not think or learn in like manner. It took me years to begin to understand genetics and other medical things related to these illnesses. Patience with self and others is necessary and challenging.

**Accept help** from other people as much as possible. Hands-on help with caring for our affected loved ones sometimes is not feasible. Sometimes, however, other people could simply sit with them in between times to allow us to run an errand, have important private conversations, take a bath, exercise, or take a few private moments. Inquire about getting in-home nursing services or respite care. All of these are needed to balance the challenges we face.

Accept that each of us is **trying the best we can** and that may be different for each of us. Accept that we may need different amounts of **self-care time**. As challenging as this is, that needs to be communicated also. Burnout is easy and is not helpful to anyone.

**Time management** is one of the greatest challenges in life in general and even more so for families with a member with health challenges. **Balance** is the goal, an often elusive one. Balance is not static so needs to be addressed often. Part of our being able to care for others is to take care of ourselves too.

If you have ever flown, the flight attendants go over a safety card. When they get to the portion about the oxygen mask, what do they say? They tell us to place the mask on our face first before helping others. That seemed selfish to me until I realized that I cannot help anyone else if I am not breathing. In that same train of thought, I cannot help my loved one if I do not rest, eat, shower, exercise and have some quiet alone time. Now we all realize this may not be as regular as before. We do still need to prioritize our self-care.

Another aspect of care is **learning what resources there are** in our local area, state and country. Finding resources could be something a friend/family member could do when they offer to help. As said earlier, being in contact with the ULF can be a major resource. They can direct you to specific people and organization who may be of assistance.

Most of all, **do not be afraid to ask questions and ask for help**. This is a new journey for many of us. At one point, it was for a new journey for all of us. Many of us may feel we are on this journey alone. *As the ULF has always said, "YOU ARE NOT ALONE."*