

Caregiving

We thank David Levy for writing this chapter.

The chapter is divided into smaller sections: What is family caregiving? Who are family caregivers? What are their responsibilities? Why is family caregiving with *dysautonomias* so hard?

Dysautonomias, like few other chronic illnesses, can affect not only elderly people but also people under 40—especially women. Family caregiving in these circumstances becomes virtually unique. Rarely do you have kids as caregivers and the amount of young men as spousal caregivers for one illness.

Family Caregiving

Family caregiving is the act of taking care of and feeling responsible for another person, loved one or family member. It is not child rearing. It is more than being a husband or a wife. It is more than being a brother or sister. Caregiving has many faces and ages, with each situation a little different.

A Family caregiver is one who feels primary responsibility for the well-being of another family member experiencing limitations as the result of a chronic disease, injury, or illness. The spectrum of

caregiving responsibilities and capabilities to create quality-of-life and well-being for another may entail emotional, physical, social, practical, financial, logistical, and psychological care and support.

It is difficult to identify caregivers, because they don't feel like caregivers. Much of what caregivers do is out of love, respect, and being "family." However, the emotional and practical wear and tear on caregivers is well documented and needs to be understood as a unique role. Love may be the motivation, but it clearly doesn't come with a set of instructions for long-term caregiving and can feel like a trap after months or years. Without understanding the responsibilities of family caregiver, many succumb to the anger, resentment, confusion, and physical ailments associated with long-term family caregiving.

While there is a lot to understand, much can be done. This is a family issue, which affects everyone in the family. Therefore, first and foremost is the need to **recognize the role of being a caregiver**. Not recognizing the caregiver role inherently prevents one from getting the understanding, help, support, and resources caregiver's needs.

Once the caregiver role is acknowledged, what happens next? Remember, we said love doesn't come with a set of caregiver instructions. Why caregiving is so hard?

- Because family caregiving involves the routine and repetitive, the day-to-day, psychological and social

issues, economics and perhaps physical care needs, and the ongoing balancing act of work, household and other activities.

- Because it is not intuitive. Your maternal/paternal instincts and childrearing experience is not substitute training for what family caregivers must deal with. We do not have a “caregiver gene” in our DNA that blossom forth when we are confronted with these issues—like new mothers and bonding hormones. Ask yourself, “What training have I had in caregiving for a chronic illness?” Probably none, and the issue goes well beyond medical or nursing activities.
- Because there are lots of role reversals – kids caring for kids or parents; parents caring for each other and so on.
- Because we wait for a crisis rather than use long-term planning.
- Because family caregivers “burnt out” and feel that they are transparent, that everyone is focused on the care receiver, but no one recognizes the effort by the caregiver. Family caregivers can feel lonely, like they are in this by themselves and that no one understands what they are going through.
- Because no one has helped to manage the expectations of what the caregiver and care recipient are going to be facing.

If caregiving is not intuitive, it should come as no surprise that people don't know what they don't know. With no instructions; no planning and no clear understanding of the caregiver role the ongoing problems get harder to solve, not easier. If you don't take a hard look at what you are dealing with you are destined for difficulty. Expectation management is a key ingredient in being a successful caregiver. If you don't balance the long term hopes and dreams with the long-term realities its tough to plan and not be disappointed.

Caregiving for a dysautonomia patient is special.

Why is caregiving for someone with a dysautonomia different?

- You don't look sick. *Dysautonomia* caregiving is further complicated because the majority of people with *Dysautonomia* don't look like they're sick. Family, doctors, friends, schoolmates and relatives have a hard time believing in the illness. It raises questions of malingering, psychosomatic illness, and "being lazy" as well as the underlying issue of whether the caregiver is being manipulated. If the illness came with wheelchairs, leg braces, crutches and a limp everyone would line up to help.
- It isn't always short term. *Dysautonomia* can affect anyone at any age. It can strike people in their twenties, fifties, nineties and for some it can strike at birth! A

chronic illness or disability such as congestive heart failure or stroke in an older person typically means 5-7 years of caregiving. With some forms of *dysautonomia* we may be talking about almost an entire lifetime, when the onset is at birth or during adolescence. The younger the individual when illness strikes, the greater the scope of impact. We are talking about lots of things being different: school, social life, relationships, future goals, responsibilities, intimacy, work issues, and the entire family structure.

Children as Caregivers

Whoever thought of **kids as caregivers**? It's true, especially with *dysautonomia*. Thousands of kids are helping to take care of their brothers and sisters and are living with the same feelings as grown-up caregivers. Kids are caregivers, because mom or dad has a chronic problem, and they are the ones at home. Kids don't think of themselves as caregivers, and they may be frightened by the confused feelings they have.

Most doctors and teachers never think about kids in this sort of role. Many parents never consider their kids as caregivers, but children as caregivers need to be recognized and supported for the valuable role they play.

Kids are the victims of stereotypes. No one considers them in the role of adults. If your children have this role, they need special support and a trusted outsider to talk to as well as Mom or Dad! Difficult stuff, but very real, and

you can't keep your frustrations and confusion bundled up inside.

NDRF has a Kids Newsletter at the NDRF Website (www.ndrf.org). It's a great place to start.

Spousal Caregiving by Men

Spousal caregiving by men can be difficult, because men are not nurturers. Historically and culturally, men expect their home-based needs to be *met*, rather than being responsible for them. In male caregiving, social and business needs are curtailed or abbreviated to accommodate the spouse.

Men see themselves as the providers and defenders of hearth and community. To see a wife or partner suffering and feeling helpless or inadequate to relieve the pain and confusion create a sense of impotency in the protector.

Sexual and other shared pleasures may be limited or lost, leaving the husband feeling lonely and unappreciated.

Lost opportunities for promotion, business travel, or increased responsibility add to the burden. The potential alteration or dissolution of plans and dreams, expectations of life imposed upon by chronic issues must be faced. The lost opportunity of an anticipated future must be grieved. The process of grieving goes through stages from denial to acceptance and may last for years. Both partners may be grieving and need each others

support, yet they may be at different stages on the road to acceptance.

Everyday life must be rearranged to accommodate the new reality and new plans laid or imposed. A new commitment must be made based on new understanding. Unresolved issues from the past with family (uncaring in-laws or parents) or with spouse (marital/sexual) may now be overwhelming. The role of spousal caregiver may not always be possible. Inevitably some will leave. Often, however, one may find great courage, strength and renewed love in this long-term commitment to stay in the relationship

Intimacy

Intimacy is important in a normal relationship. It is very important in a relationship affected by caregiving, but is greatly impacted and strained by the limitations of the illness and the roles.

Intimacy is a major issue in caring for a spouse with a dysautonomia.

You can love someone and never be intimate or sexual with him or her. You can have sex and never have intimacy with, or love for, the other person. You can love someone and have great intimacy without having physical sex. Whatever works for you is fine. If none of it works for you, or only in a limited way, you need to ask

yourselves, Is it the illness? Is it the relationship? Is it blind acceptance of the “same old same old” and the anger of not doing anything about it? Whatever the reason, the subject of intimacy is at the core of many of the issues young couples face; it is inescapable for those dealing with chronic illness.

Sex is also a challenge. With *dysautonomia* you look fine, but feel awful. When you feel lousy, you don't feel sexy. That's a real strain on any marriage or relationship. Also, having a low libido can be a problem with many people who suffer with *dysautonomia* and their caregivers.

Your Are Not Alone

Whatever your beliefs, or whether you have a formal religion, having a sense of **spirituality**, an awareness of a greater force can be a tremendous comfort. Recent surveys of caregivers indicate that one of the best coping mechanisms is their spirituality and belief in a higher power. Use this as it fits for you. Derive the comfort it can bring.

If you really want to make your relationship work, you need inside and outside **professional help**— seek it. *Dysautonomia*, caregiving and the disruption to the family unit as well as the issues of money, disability, roles, childcare, and planning for the future bring myriad challenges.

The hope of this chapter is that if you are a family caregiver you will recognize **you are not alone**. Others have worked through similar life-changing events, and there is a positive future. You must recognize your problems and actively seek your own help. No one else is automatically coming to solve them for you.

Major organizations with family caregiver support, like the NDRF, create an opportunity for defining roles, outlining responsibilities, sharing information, and gaining better understanding. Just as important as knowing what doctor to go to and what medication to try is to recognize the major burden of family caregiving, but with the knowledge that you are not alone.

Understanding this is not only helpful to those with chronic caregiving responsibilities, but their spouses, children, friends, and other family members as well.

