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Boundaries 101 for Lyme Patients

When chronic Lyme patients are diagnosed, they enter a different world, a world that is not inhabited by their families or friends. It is hard to find medical professionals that understand this illness, and those close to the patient are reluctant to believe that he is so ill, since he doesn't "look sick." Patients often have difficulty reconciling the two worlds in which they live, the world of chronic Lyme, and the world that they share with family and friends. Often relationships suffer greatly for those who are living with Lyme.

When the patient experiences a lack of empathy and understanding coming from those close to him, he may react in a number of different ways. He might spend endless and often futile hours trying to convince those he loves of the nature and consequences of his illness. He might come to doubt his own decisions, and withdraw from needed treatment. Or, he might cut himself off from family and friends, further isolating himself at a time when he really needs a support network. None of these solutions is good for the Lyme patient, or for his family.

When I'm seeing a family in which there is chronic Lyme, and those close to them don't understand, I suggest that the patient and family pay close attention to boundaries, protecting themselves from negative consequences of interaction with those who don't understand, yet keeping their loved ones in their lives. We can look at what is and is not our business, or the business of those around us, and act accordingly.

With clear boundaries in place, adults and their siblings, parents, and even grandparents can enjoy warm and healthy relationships, with respect for each other's decisions, even if there are differences of opinion. Secure adults develop an understanding, for the most part, of where boundaries are, between us and others – within our marriages, our extended families, as well as in other relationships. At times of crisis, and chronic Lyme disease in a family is, for many families, a crisis, we may turn to our extended family members and close friends for help. As those close to us become involved with and witness to the intimate details of our lives, boundaries often blur.

Those close to us might see it as their right, or their responsibility, to question our judgment regarding medical and mental health treatment. Our tendency might be to become defensive, feeling the need to justify our decisions, get others to "understand" what we are going through. When this happens, the cycle that evolves from not attending to boundary issues can be destructive to the Lyme patient, as well as to his relationships. On the other hand, when

boundaries are understood and respected, the patient does better emotionally, and he is better able to get the support he needs.

As with other life crises, struggling with Lyme disease can provide an opportunity for a patient to grow in unexpected ways. A person who normally does not seek help may begin to ask for help from those around him. A non-assertive Lyme patient may have an easy time accepting help, but has a harder time confronting someone who is crossing his boundaries.

Where boundaries are concerned, here are some strategies to consider:

- Define where you need help, and keep it concrete – cooking, cleaning, shopping, for example.
- Be aware of times when you begin to get defensive, and take that as a signal that someone may be crossing a boundary – getting into what is not their business. Learn phrases that reestablish the boundary, like “I know you care about me, but my medical decisions are not open for discussion,” or “I appreciate your help with the children, but I am responsible for their discipline. Is there something you’d like me to know about their behavior?”
- Understand what information you wish to be private. Wherever possible, hold private discussions behind closed doors (If, for example, you and your spouse are discussing choices of medical treatment for your children, and grandparents are helping out, avoid holding the discussion in front of their grandparents.)
- When there is conflict, be clear about the real issue. Is the real issue the decision you’re making, or that someone is questioning a decision they don’t have a right to question?
- Respectfully confront those who continue to cross boundaries. If they do not respect your choices, and will not accept your decisions, perhaps their involvement with you during a time of crisis should be kept at a minimum.
- Take time alone at the end of the day to reflect on the interactions of the day. If there is unfinished business between you and another person, if at all possible, discuss it the next day, and re-establish the boundaries.

Psychotherapy and family therapy can be of great help in tackling boundary issues for a Lyme patient. Understanding ourselves and how we interact with others can benefit us during the Lyme Involved phase of our lives, and far beyond those Lyme years. Chronic Lyme disease is a minefield for a patient and family to negotiate. The process of recovery is lengthy and complex.

When we seek support from others, but keep our boundaries clear, our lives are enriched and our relationships have a wonderful opportunity to grow.

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Resources

LymeDisease.org (LDo) <https://www.lymedisease.org/>

Lyme Disease Association <https://lymediseaseassociation.org/>

International Lyme and
Associated Diseases Society <https://www.ilads.org/>

Sandy's Website <https://lymefamilies.com/>