

For my wife and me, and for all the other children, taking care of Roger has been rough at times. Our life revolves around the care and attention that he needs. I think that you have to be very strong people to put up with this and still love the sick person. Muriel and I really can't do anything without taking Roger along. Even if we stay in bed for an extra hour in the morning it will make him so nervous that he starts banging dishes in the kitchen, or have a seizure. Lately, he has started having seizures in his sleep, and that has never happened before. We have no idea what is going on, and we feel helpless about it.

Our biggest need is to get some relief from this situation. Even a couple of days when we can be by ourselves. That would take the pressure off. I know that he won't like being separated from us, and it will cause him problems, but we also have our needs. It's funny, because if you met him, you would not think that there was anything wrong with him. He has a real nice personality, when he isn't under pressure, and everyone in the family loves him when the seizures aren't causing problems.

“When he's outside and the seizures come he just falls face forward on the concrete. We'd always feel so bad because we knew that no one would understand what was happening to him when we weren't around.”



We worry a lot about what is going to happen to Roger if something happens to us. We don't make that much money, but we are taking care of him right now. Muriel and I have worked most of our lives, and we have been able to raise ten children. We are a very close and warm family after all these years, so I guess we have done a lot of things right in spite of the problems.

But what will happen to him after we are gone? I know that his brothers and sisters will do their best for him, especially his older sister, but they have their own lives to lead.

We haven't received much satisfaction from the medical professionals as far as telling us what the problem is. We know that there is some kind of chemical imbalance in his brain, but no one knows much about it. Maybe there is some kind of prescription or operation that will cure the problem. One thing we won't do, however, is put him into an operation which could cost his life. Even with his problem, we want him alive and with us, rather than risking his death.

We need some help to relieve us from this responsibility, and so do a lot of other parents in the same kind of situation. I know about that, especially because of my work with Indians. I love my people across Canada, and I know that we haven't always had the services that are needed. There's always so much talk about services, and I suppose that things are better now. In the early days we were all alone with our problem and that's really rough. There are still a lot of people who are looking after these kinds of problems on their own. So many ailments and just live with them without looking for special services.

We didn't know where to turn for help with Roger, and often there really hasn't been any help there. I hope that in the future some service will be provided for people like us and like Roger. We've become strong because of him, and we know that we can keep going, but some assistance once in a while would sure help.

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