

PRIVACY, HOW DOES THAT FEEL?

by Alison Ouellette

Alison Ouellette from Windsor, ON Canada has been very active in the family support and advocacy movement. Along with family and friends they developed and implemented a visionary plan so that their son David, who lived with different abilities, could move into a home of his own. Although Dave sadly passed away in 2009, Alison continues to share his wonderful achievements, in the face of adversity, to celebrate nine very successful years in his own home. She talks and writes about Dave's everyday life, his small business, and inspires other parents to advocate for their sons and daughters no matter what stands in their way.



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We all need privacy, our own space to rest and regroup ourselves, or just have some quiet time, maybe even a little snooze. As families who have a family member with a disability we are often in a 'catch 22' situation. I want to share some of my feelings about this dilemma that we find ourselves in and I welcome any comments from other members of the Family Network. I decided to take a risk and whine a little on paper for all of us parents who have shared these confusing emotions on the subject of privacy. Privacy for us is a nebulous

under the covers. Have you ever had one of those days when you simply want to slouch like a rag on the couch or stay in bed or think I want to leave my hair a mess, wear absolutely no make-up, dress like a slob and not move off that couch or get out of bed for anyone? Have you ever felt those simultaneous pangs of guilt and breaths of happiness? I am glad to see the respite worker but truly don't want to see anyone at all! There are days when I have wanted to stay that slob. Days when I thought I just wanted to disappear.

Privacy is such a precious commodity. Most people take it for granted. I have really learned to appreciate and

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moving target. Sometimes we get it but that 'bull's eye' is extremely hard to hit and we don't get it as often as we would like. Every day when a worker shows up at my doorstep and rings the door bell and walks in the door, I experience this mixed bag of feelings; anxiety, relief and intrusion simultaneously. My

savour the moments when it is just Dave and me. I have had members of my own family; sisters and brothers say "Doesn't it bother you to have someone in your house to help with David all the time?" I want to say "YES". But I must say "No"! It is a strange feeling when I have to answer that way and cover up my true feelings.

I would love not to have that intrusion each time the respite worker comes.

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stomach tightens up and I usually sit up a little straighter. Some days I run to get dressed at that "DING" and other days I just want to hide

However, as a parent whose son needs significant care every moment of the day, I have had to live with these incompatible emotions.

I have to say "No it doesn't bother me; all the while my stomach is turning inside. If I were to be totally honest someone may think that our family doesn't need the support. How could I do that when we desperately need the help? How does that feel?"

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Some of David's workers have shared with me their own twinges of uneasiness when they walk into our house. They know and appreciate

Yes we are very grateful for the support and the sight of Dave's support worker walking up the driveway. Some days I absolutely can't cope another minute without them. We admire and love these people who provide David with the excellent care and support his needs. Meanwhile we try not to get too attached because they come and go so often. It hurts when a worker leaves.

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I can tell by the way Dave hangs his head that he is sad and depressed when they leave for another job. There have been moments when I have anxiously looked out the window and wished it was one hour later since that's the time she is scheduled to arrive. But when that time arrives, our family undergoes the undeniable interruption in our family privacy.

David's brother and sister always ask, "How come it always turns out that the worker is arriving just when you are

yelling at us? Mom I feel so stupid when that happens." I know my other children felt uneasy whenever there was a new worker. They loved some helpers like a family member and others would not even give them the time of day because they were only working with Dave.

the fact that our personal privacy is intruded upon every time they come through that front door. They try not to intrude but their very presence makes it impossible to ignore. They always respect our privacy but they need to appear now and then as Dave wheels from room to room in the house. With a mixed feelings and a deep sigh I have learned to manage with the dinner and the

bed time schedules that workers appear to support our family and Dave. We have learned to treasure the time when we do have our family privacy. The private time to yell and scream at will or to dance around the house if I'm in that funny mood. We love the privacy of snoozing on the couch with no-one interrupting to ask a question.

It is very difficult to live with these conflicting

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emotions but believe me they are real and normal for our family situations. What I have learned is the power of connecting with other families and sharing these feelings is very helpful. These connections can never be underestimated.