

BRIAN'S STORY

Brian is a friend of Chris and Chris's advocate. He was originally introduced to Chris through PEI Citizen Advocacy.

My name is Brian and I'm 24 years old. My friend, Chris, is around 39 or 40 years old. I live about 20 minutes away from the very large institution where Chris lives. I have known him for about nine months. I just consider him a friend. Chris does not verbalise a lot which makes it more difficult to read his feelings.

On Chris's unit there are approximately ten other people. They have a variety of disabilities. During the day time they sit in a large social room a lot of the time. Chris shares his bed room with another man.

Chris was in a group home. Then he had some nursing needs and he ended up in the institution. I know that he's been in there more than six years.

Chris is often in bed when I go to see him. Otherwise he is sitting in the social room. The last few times I've been to see him in the late afternoon he's been in bed. Every time I go in there I take magazines for us to look at and I took him coffee last time. He seems happy ...but it's hard to tell. He's been there so long, his expectations would be pretty low, and it is difficult to read him.

In the summer I take him for walks. There is a volunteer program at the institution which runs activities. The activities seem to be geared to seniors though. There is nothing individual for him. I know they have bingo sometimes and I think he goes downstairs to a big room to sing. Although, I've never seen him down there.

I don't think Chris gets stimulated enough....like mind stimulation. I've never been there when he's doing anything. Sometimes when I've arrived to see him he has one of those children's abacuses, with the bright coloured beads on bendy rods, in front of him. They've plunked it on his wheelchair table for him to play with

...and he seems really angry that it's there. As soon as I move it, his mood changes.

I don't think it's the nicest place for him to be in. He needs more one-on-one attention. When I go he gives a big smile because he sees someone whom he knows and recognizes. He just loves looking at the magazines and sometimes we look at my photo albums. If he was in a group home he would have more independence and maybe he would get out and just do more general living day-to-day things like going to the grocery store..... rather than being told when to get up, when to eat and when to go to bed. Maybe, if he had more independence he would verbalise more freely about what he wanted to do and when. Is there not a Public Health Nurse who could visit him and attend to his nursing needs in a community setting?

You ask whether people can come and visit him. Well, not exactly. The institution didn't like the idea of me visiting as a friend. They wanted me to become a volunteer to the institution and volunteer through their program. There was a big meeting with the hospital staff to work out an arrangement through which I could visit Chris. It's crazy. Because I'm not a family member it's been a big ordeal. So, it's actually complicated for people on Chris's unit who may have friends who want to drop in.

As far as I know nobody goes to see Chris except for me and his legal guardian. His guardian is not a family member.

One thing that would really improve Chris's quality of life is some one-on-one company for a few hours each day. But the institution doesn't have the staff for that. It's so sad he's in that place...there's no quality of life there for him.