

PHOTOVOICE

Calvary Health Care Bethlehem patient Scott and his mother Wendy talk about the powerful impact that Photo Voice has had on Scott's quality of life since his diagnosis with Huntington's Disease two years ago.

Speech and communication therapy has an important role to play in the management of communication problems in PND. As the disease progresses the effectiveness of communication becomes increasingly compromised. Interventions such as Photo Voice can be timely and responsive to the changing needs of the individual and to the challenges faced by the family.

It is vital to understand the value and importance of involving family and caregivers in developing and facilitating effective communication strategies. These are well recognised for the positive impact they can have on the overall well-being of the individual with a progressive neurological disease (PND).

Huntington's Disease (HD) is a progressive neurodegenerative disorder. It is one of the PND's that also affect many younger adults. The combination of progressive changes in physical abilities, thinking, speaking and behaviour has a profound effect on the individual's ability to communicate and connect on a daily basis.

After a life-changing diagnosis of HD in 2015, 32yo Scott progressively felt his social network of friends slip away. Previously a high level sportsman and working as an accountant, he led a very active social life so it was a powerful change to "re-open doors with friends." Scott's mother Wendy attended the program with Scott and didn't want the 4 weeks to come to an end. "Photo Voice was so enjoyable for Scott and I to be doing something together that was not just ordinary every day, We really looked forward to it and involving family and friends through photo sharing and facebook has given Scott a focus each day"

PHOTO VOICE QUOTES

Scott Ashworth age 32 HD

It was good for my communication and it re-opened doors with friends.

I need to keep going through my "staying connected" groups on Facebook.

Wendy Ashworth (Carer participant, mother of Scott)

Of all the appointments we have to do with HD, Photo Voice was the most meaningful for Scott and I.

We were able to connect socially with a new group of people which gave Scott opportunities for interactions that are increasingly rare as his HD progresses.

Photo Voice gave a new focus to each week as we explored the given theme for the week and talked about the possibilities for photos.

Photo Voice was so enjoyable for Scott and I to be doing something together that was not just ordinary everyday. We really looked forward to it and involving family and friends through photo-sharing and Facebook has given Scott a focus each day.

Interview conducted by Nicki Jackson – Speech Pathologist and trained PhotoVoice program facilitator.

Scott and Wendy – Participants in “Photo Voice” 4 week program May 2016.

Nicki: We’re just talking about the Photo Voice group that you guys participated in this year. You both came together as part of this group and we had about four people plus carers. So Wendy if you want to tell us about what your thoughts about participating in the group were and how it helped both Scott and you?

Wendy (Scott’s mother): We both really enjoyed it, it was something that we could do together and it was a really good social thing, wasn’t it? We were able to just go out and do something together and interact with other people. We don’t get a lot of opportunities to see other people. We see family, but people outside of that we don’t get to see all that often. The people that we worked with were fantastic. They were all lovely and all loved Scott. We looked forward to it every week, it was really good.

Nicki: What did you think Scott?

Scott: It was good to get out and be social with people about my age.

Nicki: What did you enjoy most about the group? What new skills and techniques did you learn to help you stay connected to other people?

Scott: More Facebook skills, how to communicate with people, to put photos online.

Nicki: How has that helped you?

Scott: Just got more reaction from my friends.

Nicki: Prior to doing the group had you found that some of your friendships had fallen away a little bit?

Scott: Yeh, definitely.

Nicki: And has that changed now?

Scott: Yeh, a bit.

Nicki: Something you’re still working on?

Scott: Yep.

Nicki: So when you do post a photo, it establishes that connection again with those friends?

Scott: Yep, definitely.

Nicki: What else did you do in the group?

Wendy [to Scott]: What’s this fantastic book you came up with?

Scott: My book, about me.

Nicki: How have you been using that book?

Scott: Just able to communicate better with people. Like my Aunty, when she arrived.

Nicki: She could have a look at all your great photos in there?

Scott: Yep.

Nicki: So some were old photos and some were new.. Of things you'd been doing around your local area?

Scott: Yep.

Wendy: It got us out and about too. We went to visit all those places that were special for us. It made us really focus on them by taking photos. It was great.

Nicki: Exactly. In terms of all the services offered here, how do you think this particular offering of the Photo Voice Group... how do you think that fits in, and how do you feel that that's an important thing for managing health?

Wendy: This has been the best thing that has really been offered to us, because it was an ongoing program instead of, you know, instead of every 3 months. It was week by week so we had that continuity of social interaction with other people. And the other things are just medical appointments, we come and have a chat and a bit of a review and go away. This was something that really made us feel good, we looked forward to it each week so it had really positive effects for both of us.

Nicki: And the fact that Wendy, you got to come too, do you see that as important?

Wendy: Yes, yes that was great for me. Seeing and giving Scott the opportunity to interact with other people, because we don't get a lot of that.

Nicki: ...and as you say, it generated things for you both to do between the groups as well.

So what sort of photo projects did you do in between the groups?

Scott: Lots of pictures at Torquay and Upwey

Wendy: where we live

Nicole: Is that what maybe got you interested in moving to Torquay? You went and explored the area a bit more?

Wendy: Yes, we did! We were only visiting but it got us out and about to take photos and really concentrate on the place.

Nicki: and lo and behold, you're moving there!

Scott and Wendy: Yes!

Nicki: I wonder if there's anything in that.

Wendy: Yes, a very positive force it's been!

Nicki: So you both think that this type of intervention which is really focusing on health rather than the disease itself, you know, health through staying connected with family and friends through communication.. You both see that as a really important goal?

Scott: Yes (nodding)

Wendy: Absolutely, the most important thing we've been able to do!