



Our granddaughter Saskia takes a photo of Paul and me! (December 2011)

How am I now?

Christine Bryden

I feel very honoured to be invited to write this piece for your magazine. It has been a few years since we travelled to your beautiful country, but we are looking forward to visiting again later this year. So many changes have happened in Japan since our first visit in 2003, and I am so impressed by how much attitudes are changing, and people with dementia are speaking out.

For me, though, the years since going to Sapporo in 2007 have been very difficult. The highlight of Sapporo, as Paul (my memory bank!) tells me, was meeting the Gotos and Kawakubos. Their subsequent visit to Queensland made a huge impact on staff and care-givers here. But it was a bleak time for me – I was feeling so low, and could not really appreciate this amazing event. For a couple of years, I was finding it hard to eat, to concentrate, and to cope with increasing executive function decline. I was losing weight, feeling increasingly anxious, and extremely overwhelmed by trying to cope each day. But in late 2010, I was encouraged by Paul to think about travelling once more, to Greece for an ADI conference, after my mother's 90th birthday in the UK. I met once again friends from around the world; friendly faces from so many different countries, including Japan.

In March last year, I was invited to give the opening plenary address at the international conference in Toronto, so we travelled once more, again visiting family in the UK and Belgium. The delights of meeting friends in the Alzheimer's movement were somewhat dampened by knowing that only shortly beforehand, Japan had faced the terrible earthquake, tsunami, and nuclear breakdown. But still I spoke out about how much Japan had achieved, giving it as an example of an ADI member country that had changed in its attitudes to people with dementia. No longer were we the demented elderly; instead we were spoken of with more respect as people with cognitive deficits.

For me, despite recovering my health after the terrible two years of 2008 and, 2009, the last two years have also been very difficult. My mother died after a long battle with dementia and other illnesses in 2010, and my aunt died after a

short battle with cancer. These losses and the grief are hard to cope with, when my own battle continues relentlessly.

Life is becoming much more difficult, and Paul needs to be even more patient. I cannot plan ahead, nor recall even this morning or yesterday, and I am so frustrated with my inability to think clearly, let alone speak properly. It is so hard to try to describe what this feels like – this endless struggle to think where I am in the flow of time, and what I am meant to be doing, let alone what I just did.

Words come out in a true jumble – just rubbish at times. I don't know how Paul manages to know what I am trying to say. Handwriting is a scribble - just a muddle of letters. I can't even count money any more, and make lots of mistakes with our finances on the computer. Paul is an amazing man, keeping me trying to cope by encouraging me, and letting me do as much as possible. It is really embarrassing to be honest about this, but sometimes my struggle to cope with daily living is so overwhelming that I scream and shout, use bad language, and behave like a spoiled toddler. I am so amazed that Paul still puts up with me!

Now I am also trying to take notes, track ideas and make detailed plans for my third book. There is so much to catch up with since writing the second book in 2004. It is a daunting task, but one which will exercise my brain, and keep the neuroplasticity happening. My most recent scans show quite advanced brain damage, but obviously I can still write and speak – just not very clearly sometimes! I am working hard at re-wiring my brain, all the time it is un-wiring, so it's not all downhill, but a roller-coaster ride of changes and challenges.

I look forward to seeing my friends in Japan later this year.

Christine January 2012