'How can technology help us to hear the voices of people with dementia?'

Claire Craig
This afternoon

• Interactive session
• Exploration of how everyday technology can help us to hear the voice of people with dementia
• Focus on technology as a means of sharing experiences, building relationships, promoting wellbeing
• Look at a range of examples, consider what is already happening, possible challenges and ways of helping individuals overcome these to tap into this media
Why is this important?

Descriptions of dementia frequently focus on definitions of the condition and the associated changes in cognition, memory and communication.

However the real story as told by people with dementia and their carers is about the impact of these changes, the growing isolation, shifting relationships, limited opportunities for choice and control.
Technology as a medium for communication

Technology can act as a powerful medium for communication, providing the person with a voice, a very public voice where experiences can be shared with others, a way to communicate what is important, provide the person with a means to capture a glimpse as to core values, facets of personality and the challenges faced.

Technology can provide a means to help others understand how it might feel to stand in the shoes of a person with dementia.
What technology can offer

• Space
• Meeting place
• A different way of communicating: metaphor
• Medium for self-expression, catharsis
• Record and an agent for change
• Tangible reminder of who someone is
What does this technology look like?
Focus for today

- Internet: blogs and wikis
- Camera and digital picture frames
- Digital scrapbooking
- Video: video portraits, digital stories
- Web-2 technologies such as You-tube, social networking sites
A new year has arrived, and I have decided to use my blog as a tool to help me gauge my condition throughout 2008. Hopefully, at the end of the year, I will find little decline.
Currently, I must say that my short term memory is very poor. I don't recognize my vacuum cleaners. The other day, I "found" a missing dinner plate in the refrigerator. (I bet I'm not the only one guilty of that!) I recognized the plate, but not the pieces of deluxe pizza on it. I don't remember having ordered a pizza, but my husband tells me we did. Whole conversations are lost to me. My husband has to continually remind me about them.
Possibilities

- Outlet
- Speaking out into the ether
- No responsibilities
- Not being judged
- Letting others know how it feels
- Good for individuals who can write and use a computer: are other possibilities such as gabcast
Photography: simplest level

- Standing in the shoes, sitting in the chair, of a person with dementia
- Helps others revisit and understand challenges facing a person
Shifting locus of control

- Sensecam: wearable digital camera

The v2.3 SenseCam shown close up and as typically worn by a user. The model pictured here has a clear plastic case that reveals some of the internal components.

Example images captured by SenseCam.
Photography: working with the person with dementia

- We are sitting together in the dining room at the hospital looking through the photographs Enid has taken of this new, alien environment. 'This picture is of my living room' she says. She points to one of the other residents in the image with the words, 'he is one of the painters here and this is one of the people who lives next door.'
We turn to the next picture, which is of her bed bay. She pauses for a moment, thinking and then pointing to the blue lino she simply states, 'that is the moat with the house where I live'. I am suddenly reminded of her reluctance to move from her room and ask whether she likes it there. 'Oh no' she says. 'I never learned how to swim.'
Offering an alternative language
Shared experience

"In every conceivable manner..."

Who are You?

You look out at us from the photograph. We see our daughter in the little girl at your side. We see Brack's mother reflected back in the baby's eyes.

Yet we can't be certain of your identity. The writing on the back of the photograph is in illegible German. Yet our family smiles back at us. A family who had no idea what was to come. A family who lives on in our children. You lost everything when you escaped Germany. Now you have even lost your identities.

Bridge to our future. -- Alex Haley
I have just recently bought a computer program which will allow me to do digital scrapbooking. This is a wonderful invention for people such as myself who have a short term memory problem. It is easy to use.

It is allowing me to go back to the myriad of pictures I have collected and stored on CDs to select the best for my "albums". Currently I am working on my Alaska album.
Control and self-expression

This program allows me to change backgrounds until I find one I like. Then I can arrange pictures and embellish them with corners, flowers, flourishers, etc. I can journal anywhere on the page I wish. With all the choices I have, my mind is exercised to its max.
I strongly recommend early onset dementia people to get out and take pictures and put them onto some type of digital scrapbook. Your mind will used through making endless choices and critiquing your work as you go. And, in the end, you will have something to show others and to be proud of.
Technological advances

Mindbook: digital scrapbook – a multimedia package that enables people to create an online repository of memories including photos, letters, cake recipes, and even musical clips.
Telling a story

- Digital storytelling
- Empowering experience
- Equal relationship
Video Portraits

• Eliza......
Sharing: public spaces

• You tube
• Social networking
• Breaking down stigma, finding like minded others
Finally...

- Everyday digital technology offers many opportunities to hear the voice of people with dementia
- Challenge is to share the range of possibilities available and support individuals to access and use the medium that works for them