

The My Life My Story project focuses on reminiscence. Whether or not we realise it, reminiscence plays an essential part in all of our lives. For example, a particular smell can suddenly remind us of a special time or place - for me, the smell of mothballs always transports me back to holidays spent at my aunt's house in Watson's Bay. Or another example is when an old song we haven't heard for years comes on the radio and we can instantly recall all the words and we're able to sing along as if it were only yesterday that we last heard it played. Each line tumbles out of our mouths without any effort at all, and we are left with a happy feeling at just hearing that song again and the sheer wonder of where the memory for all those words comes from!

Reminiscence has particular relevance to people living with dementia because for most people affected, as dementia takes its course over several years, memory loss will be their most obvious deficit. At first, it is usually only the most recent, short-term memories that are affected, with older memories remaining intact. But over time, as the effects of the person's brain damage become more global, dementia will erase even those older memories, a little like peeling away the layers of an onion, until only the very oldest memories remain. Whole periods of a person's life will disappear from their consciousness and this ofcourse is devastating to the person affected, and for everyone around them.

So for much of the disease, recalling older memories helps the person with dementia make sense of their world. Older memories are usually clearer, more intact and easiest to recall. It is for these reasons, we so often find people with dementia talking about their past. Older memories can often put the person at ease and give them a sense of comfort, especially if they are given the opportunity to communicate those memories freely to others.

The primary aim of the My Life My Story project was to produce personalised DVDs focusing on the lives of people living with dementia, in order to encourage reminiscence. Similar to the 'Life Story' scrap books or albums already commonly used in dementia care, the DVDs are different because they apply modern technology capable of producing a more dynamic result, incorporating a range of different mediums.

The project provided an opportunity for each person with dementia to record important aspects of their life. We particularly wanted the person themselves to choose what was included, with the assistance of family and friends. It was intended that gathering and compiling items for the DVD would encourage enjoyable social interaction as different phases and significant events of each person's life were discussed and recorded.

Participants were able to use photographs, home movies, favourite music and other memorabilia such as certificates or academic degrees to create a lasting record of their life. And because of the type of technology used, several copies were able to be made for family members and friends. Paper copies of original photographs were also produced and various materials for a 'Life Story Book' given to participants or family members if they wished to compile a book based on material used in the DVD.

The level of involvement for each person with dementia depended on either their level of impairment, or willingness to take part. Some participants were able to make many of the decisions about what aspects to include in the DVD, while others had those choices made by family members on their behalf. But as you will see in the first interview with Alan further on in the presentation, even though his wife Lyn wasn't fully involved with choosing which items to include, she has been able to thoroughly enjoy the DVD, watching it several times with Alan and other family members and marvelling at her own achievements. And as Alan mentions in his interview, watching the DVD has stimulated conversations between the two of them about past times, both happy and sad.

As you might imagine, the 'character' of each DVD has been quite different from the next. The last DVD you will see today reflects the vision of both the person with dementia - Col, and his wife June, who very much wanted the DVD to focus on their life together, especially their travels and dress-up parties, while at the same time highlighting Col's engineering and other achievements accompanied by a range of musical styles.

We believe that producing a DVD like this, with the involvement of the person and their family, can assist in empowering the person with dementia by focusing on positive aspects of their whole life, reminding them that they are a worthwhile person. By highlighting their unique achievements and appreciating their contributions, as the DVD is watched by the person themselves, and their family and friends, we also believe that the DVD can help to reduce the degree of stigma surrounding their dementia.

The DVD Life Story concept was originally conceived by Trudy Neal, a former Dementia Advisor with Catholic Community Services. Her inspiration came from observing the successful use of Life Story books with clients in different settings. Trudy could see the potential of using other technology to bring about a different result incorporating items other than photos.

The project was implemented across three Northern Sydney regional areas with funds provided through the Australian Government's Dementia Community Support Grants.

Other Catholic Community Services staff members - Coordinator David Lo, and two other Dementia Advisors - Roxanne Chant and myself, were involved with the project. David was primarily involved with the scanning of all the materials for each DVD, and he has been particularly diligent with this task.

Hundreds of photos, certificates, degrees and documents have been scanned, video footage and home movies copied and inserted, and many pieces of music downloaded. A huge degree of patience has been required while participants gathered together material and made important decisions about content. All have been transformed by Trudy's husband, Col Neal, our hardworking and painstaking volunteer, who had the technical expertise to bring the project to life and has been ultimately responsible for each DVD. Col has spent many, many hours compiling, composing, tweaking and finalising each DVD to meet each person's requirements.

Seventeen people participated in the project, which had an official time-frame of approximately 12 months.

Ten participants were drawn from the general community and three came from culturally and linguistically diverse communities - one person had a Pakistani background, another was Chinese, and another participant came originally from Lebanon.

We actually found it a lot more difficult to find suitable participants than we first envisaged. Ideally, we were hoping to find participants whose level of dementia still provided them with enough awareness to fully participate in choosing the content of their DVD. They also needed to be willing to put their life on record and I might point out that the concept of doing this isn't everyone's cup of tea.

In other instances, getting involved with the project, wasn't always appropriate for people's circumstances - initially, some families expressed great enthusiasm for the concept, but understandably, as life threw up other competing priorities as so often happens when dementia is involved, they decided they simply didn't have the time to take part.

Five people in the project had younger onset dementia, meaning that they developed their dementia under the age of 65. I think this project was probably particularly confronting for younger participants and their families, as it highlighted their more unusual circumstances, and a life that will undoubtedly be cut short by this awful condition.

The film footage you're about to see contains interviews with Alan, husband of Lyn, who developed younger onset dementia at the age of 55 and who has lived with her condition for 15 years. Part of her life story is shown in actual DVD excerpts following Alan's interview.

The two interviews following Lyn's DVD, are with Col and his wife June, talking about Col's DVD, and then we'll see three excerpts from his DVD to finish the presentation.

I'd like to make a small apology here for some glitches in the sound and wording at the end of Col's DVD - it doesn't happen on the actual DVD itself, it's related to copying the DVD excerpt across into other film footage.

If you would like to ask me more about the project, I'll be happy to answer questions following the last session at 5 o'clock today.

Mary Clifton

Co-ordinator, Dementia Advisory Service

Catholic Community Services NSW/ACT

T: 02 9811 5250

M: 0434 605 685

E: [mclifton@chcs.com.au](mailto:mclifton@chcs.com.au)

[www.catholiccommunityservices.com.au](http://www.catholiccommunityservices.com.au)

Strong Lives, Inclusive Communities