ECH enriches the lives of older people through independent living units, community services and residential care.

Living On with Early Stage Dementia
Consumer Consultation Project 2007 SA
Katey Elding Project Officer, Service Development

A Dementia Community Grant Project
An Australian Government funded project helping Australians with dementia and their carers.
In Partnership With...

In God we trust,
All others we need data.

W. Edwards Dening
What’s a Memory?

• What does it mean to lose a memory?
• What remains important to the person and their carer?
• How can services respond whilst maintaining identity?
A Qualitative Narrative Approach

Listening to and using the stories of people with Early Stage Dementia and their Carers.
Where?
Something as precious as gold, young man, something as precious as gold

…it quite startled me because there was no effort… before …everything has become hard work just coping. I suppose it’s silly in a way but I’ve always read a-lot, I’ve done puzzles without help. Of course, I was top of the class, but to find things like that hard to do, really flattens you…

(Person with Dementia)
‘So, I’m hoping I’m going to be able to cope with things … When you’ve had a brain that works magically, and all at once it doesn’t…when it feels as though the thought won’t stay there long enough to just deal with it. And I’m standing there open mouthed ‘Alright, what was I here for?’.

It’s a horrible feeling. Has anybody else told you that?’

(Person with Dementia)
Something that makes you cry, my boy, something that makes you cry?

‘...sometimes I’m eating and the hand gets a bit shaky. It’s very frustrating when you go out and you try to eat something (eg beans and peas) and you can’t pick it up and people say, ‘Oh, get a spoon, we’re not embarrassed’ but I am’.

(Person with Dementia)
I’d rather talk about the weather!

‘I try to avoid telling people, even my brothers and sisters don’t know… I keep thinking perhaps I’ll be feeling a bit better one day and I’ll be able to tell them’.

(Person with Dementia)
It’s a very scary business!

‘The experience was one of horror, disbelief and denial on the part of me’.

(Carer)
What remains important to the carer?

I’m a bit nervous about the future. What will happen to Mum? Because, no-one’s really said what will happen to Mum… once you know … what to expect it’s a bit easier…’
What does it mean for carers?

‘... even for our family to understand. I’ve tried a couple of times to get my son to come to things and he finds that really difficult... he can’t do it, so he really doesn’t understand... and that’s one of the things that I say about the children... we see them in a social situation for two hours or so and he’s fine and they don’t see the every day side of him and what goes on’.
Then she started to remember ...

‘I make sure that everyday, I learn something by heart. Now this is something that my specialist told me that I would be unable to do. But I can you see. I can do it and I continue to do it.

Everyday I learn something new by heart’.

(Person with Dementia)
On their own!

If I was getting lost in a particular shopping centre, I will walk and walk and walk through that shopping centre, time and time again till that is put back into my new memory... To me, it’s just another challenge.’

(Person with Dementia)
Walk right in sit right down, 
baby you can drive a car!

‘I don’t want to get in the habit of calling a taxi just to go to the shops… They could spend it on someone else and I’ll get my exercise’.

(Person with Dementia)
It’s the simple things in life...

‘The first day I got there, I wiped the dishes. I didn’t have to because they really don’t want anybody to do it, but me, I’m determined, I wanted to do it… I wanted to do something positive’.

(Person with Dementia)
Decision Making

‘...she was so well organised about the whole thing. I think she was going through all this and organising it all beforehand. She’s never wanted to be a burden on anyone so she wanted to make sure that she had sorted all that out. She’s done a really good job’.

(Daughter)
What next?

‘I’ve never been a group person… the men’s group, I found it interesting and I enjoyed it…we have a little chat and then we get up and start doing things … so we enjoy each other’s company’.

- Targeted early intervention programs to maintain or learn new skills eg vocabulary
- Support participation in valued roles, meaningful activities, helping others, social connections
- Multiple options eg case management rather than cleaning
- Maintain decision making
- Flexible services eg evening education for families to access
‘Be positive in your approach to everything. Even if you feel you’re not achieving, just keep trying. If you can’t achieve in one area, re-look at your options and move to another area… don’t just see yourself as a failure because you can’t do it. A person may have been an excellent cook at one particular time. They may have lost the ability not to cook, but they may well have the ideas still within their head as to what to do and they could sit down and write out recipes so they can pass them on’.

(Person with Dementia)
‘And the two of them smiled and smiled because Miss Nancy’s memory had been found again by a small boy, who wasn’t very old either’.

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