

Gerontology Conference –26th July 2005

Thank you to those whose voices are expressed here, in particular, Jacquie and Jim for your support and contribution.

Resilience and Vulnerability- what people with dementia and their carers have to teach us.

This paper is informed by interviews with three carers and a person with Alzheimer's disease. Each of them has shared with me some of their experiences, what they valued in terms of support, what they felt undermined by and what those who provide services can do to support them. Each of them is resilient.

"Resilience derives from the Latin *silere*, which means "willow". "Its meaning therefore is to be infinitely flexible, "to spring back." Here it must be distinguished from the strength of the oak. For as Jim said, "when the floods come, the oak can be uprooted but the willow will not break."

Each of us will have been personally touched by people who are examples of resilience and courage. In my years as a social worker at Domiciliary Care Service I have met many people who have suffered deeply because of personal tragedy: the death of children, parents, siblings, chronic debilitating ill health, emotional and financial deprivation, abuse in all its forms, precarious housing, addiction, cognitive and mental health problems. These experiences often occurred in the context of world events: War, the Depression, racism, political and social climates that produced ostracism and genocide and exile from country of birth and family.

They have needed to find ways to survive and live with these experiences, to rise above rather than be consumed by them.

So many people stand out for their grit, determination and tenacity, for their resilience even though they are vulnerable in the most telling ways. People with dementia are particularly vulnerable, both personally and as members of society. They become reliant on others to see past their diagnosis. Those who care for them are also deeply vulnerable.

Recognition of both resilience and vulnerability is deeply important when we work with people who have dementia and their carers. This presentation can only touch the surface of the complexity of issues and experiences faced, and of what gives meaning, purpose and hope to lives impacted by loss and grief, yet also strength of spirit.

Victor Frankl wrote in *Search for Meaning*, "It's not the events in your life that determine who you are, it's how you choose to respond to them." This is pertinent when I reflect on the people I speak of today who are for me, examples of resilience.

What they shared acts as a guide about what they need from people who provide services. It provides impetus for reflection. They are saying how important it is for us as service providers to be conscious of our impact, that what we think, say and how we work with them can support their resilience and it can undermine them and make them even more vulnerable.

Stories of resilience-the capacity to keep going

1 Max was totally dependent on Jacquie in the last years of his life. He could not walk, talk or convey his wishes. She anticipated his every need. She used a vast array of equipment to assist her with his personal care and re-oriented her sleeping patterns to fit in with his quiet times. Jacquie experienced times of deep despair and attributes this to "sleep deprivation, exhaustion and not being able to think straight." But she loved Max and wanted to "surround him with the things he loved, music, art... to reassure him with touch, not have him lying in a nursing home looking at the ceiling."

2 Pat and Andrew were happily married. He was a loving and gentle man and Pat who had chronic health problems, attributed her very life to his care. In his 50's Andrew began to change,

becoming unpredictable and agitated. Pat felt isolated and afraid as she tried to deal with his increasingly erratic behaviour and the added burden that no one believed there was anything wrong, “they thought I was neurotic or it was marital difficulties.” For Andrew seemed much the same to family, friends and doctors. It was many years before he was diagnosed with Alzheimer’s and he spent years plagued by hallucinations and terror.

3 Sophia was born in central Europe and lived alone in a house with a big garden and multi-coloured chooks. She has a significant dementing illness and began to cross the main road outside her house without looking. After a fall two years ago, she was admitted to hospital. Placement seemed the only option. Her son came from interstate on a routine visit and faced with this situation, made the speedy decision to stay and live with her for a time because of her deep attachment to home and because “it felt like the right thing to do.” This was difficult for he had work and family interstate. Residential respite enables regular visits home but when in respite care Sophia spends all her time looking for the exit door that will take her home.

4 Janet’ voice –“I am aware all my waking hours that I have Alzheimer’s. I am over the initial horror. I don’t think there is very much I say or do that doesn’t remind me of the future I have got....in the early days it was like an abyss. I would wake up in the morning and my future was laid out before me-a blackness. It is still there, but its grown lighter..... You are part of that world I am going into because people like you are going to look after me, be there.... I said that with sarcasm! (I asked her “shall I put that in?” “Yes” she said) and I will turn to you. And that is not what I thought my future would become. It is very difficult because if I say ‘leave me alone’ that is not what I want, but I do want to be allowed to try things.”

These carers are thankful and appreciative of the help they receive(d) from community services. Janet knew she needed help and at the same time, dreaded being taken over, patronized, and ignored.

Experiences they have found undermining

Although they praise many of the staff they also experienced attitudes and opinions which had a deep and negative impact upon them, as examples:

- “You are constantly encouraged to relinquish care, people would say to me, you don’t have to keep going, you can give up you know....or you can’t look after someone like this on your own....The words stick right in you. They’d come to mind every time something went wrong. I’d think, she’s right, I can’t do this. And I’d hate her. I’d be filled with self-doubt, lack of trust. You lose balance”.
- “They (service providers) shouldn’t make judgmental comments. If they are going to say something like that, say nothing. Or give praise....value judgments are so undermining, so insensitive.”
- Another described a well meaning friend - “who was always ringing me and pushing me that I had to put him somewhere....she had run a hospital somewhere and she was very pushy. I thought well she must know and that was one of the things that worried me...and my heart would sink and I’d think, no I can’t.”“The silly part is I feel guilty because I’m not putting him somewhere. But everyone seems to think I should, except you girls, you understand ...but I think most people think that I am wrecking myself, by keeping him home too long and I’m in a quandary about that.”
- Sophie’s son reflected that it was very difficult to have to make major life decisions without warning and he wished services had been put in place earlier, for perhaps this would have impacted his mother’s habits and responses in the world.

Such experiences show how easily service providers, friends, family, can seriously undermine resilience without being aware of it, even with the intention of being helpful.

What They Value In the Support They Receive From Service Providers

- “Knowing you were on my side, it gave me confidence”...
- “Reminders to show care for myself....I was so focused on him I wouldn’t think of it”.....
- having people with “expertise, who knew what they were talking about to seek support from, who understood me and respected my wishes”
- “the relief when staff came” who I trusted and “who understood the problems we faced”
- practical and emotional support and guidance with difficult and complex issues
- feeling supported and cared for
- feeling safe to share how hard it is without simplistic reactions
- Creative and lateral solutions to difficult problems, for example, Pat’s friends were important to her but Andrew was very jealous, so regular respite visits were arranged so that Andrew had support and Pat and her friends could paint a little.
- “I’m quite happy pottering along ...I couldn’t do it without all the help I’m having.”

What are they asking of us?

Relationships

They are asking:

- for ongoing “consistent” relationships with service providers they can trust,
- that we be sensitive to the nature of the relationship between them and those they care for
- that we see beyond the frailty of physical and cognitive compromise and symptoms
- That we recognize that life and relationships have many layers and that there are many ways to understand and to touch people in the deeper reaches of their being.

Skills based on respectful attitudes, values and assumptions

They are asking:

- that we do not make judgments based on appearance and behaviour
- that we listen deeply, understand and explore with them what is possible
- that we seek to understand the meaning of what they are doing from their perspective
- that we do not undermine them by being negative
- that when we feel concern for their well-being, we offer our perspective from a place of genuine concern and enquiry
- that we bring our expertise and experience to assist them, to help them explore, solve problems and make difficult decisions
- that we do not presume to know what is best for them, but recognize that it is their lives, their beliefs, values, wishes and desires , we are working with- it is not appropriate to impose our own values and beliefs upon them
- That we recognize their vulnerability and that this may show itself in many ways, for example in the way they express themselves and behave.

As service providers we play a relatively small part in relation to the bigger picture of clients and carers lives. However, this is at a time of great vulnerability. Our work with people and systems is often fraught with social and ethical dilemmas. Situations are often complex and seemingly irresolvable.

In summary, these voices are saying that:

- The nature of our skills and relationships is extremely important to them.
- The way we work with them is critical – are we working with them or imposing upon them?
- The values, attitudes, assumptions and beliefs we hold are deeply important. Are we being respectful or dis-respectful? Do we make judgments because they do not behave the way we think they ought to?

In order for respectful practice to be possible across the service system sector, both private and public, and not just in the hands of individual service providers,

- service delivery structures and systems (from the highest levels to the ground) need to support the creation of a culture that values clients, carers and service providers alike,
- that supports excellent practice at the coal face, which is where it touches people's lives,
- That focuses its energy on supporting what it means to be truly client centred in our work.

The social and ethical dilemmas and resource limitations will always exist, but surely we are in a better position to respond to them in a climate of mutual respect that values the inherent worth of each person's life.

Postscript

- Jacque cared for Max for 7 years. He died at home.
- Pat cared for Andrew for 10 years but eventually had to make the decision to relinquish care because of the toll on her health.
- Sophia is still at home. Her son travels interstate to be with family and she continues to look for the door to home.
- Janet deteriorated quickly. She has since died.

Thank you

Colleen Lamshed
Social Worker/ Service Coordinator
Metropolitan Domiciliary Care Service-Eastern Region
207-255 Hampstead Rd
Northfield. SA 5085

Email: colleen.lamshed@state.sa.gov.au