A decade of change

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Alone with my fear

- Diagnosed 1995 at age 46
  - single, two young daughters at home

- Life changed overnight, fearful of my future

- Alzheimer's Australia supported only carers

- Stereotype of mindless empty shell
  - Would that really be me? How soon?
  - What would happen to my girls?

- Wrote about my fear “Who will I be when I die?”
Feeling valued and connected

- Less depressed by 1998, chose to be positive
- Approached ACT Alzheimer's for help
- Welcomed by wonderful Michelle McGrath
  - Met weekly with a few other ladies
- Michelle made me feel like a co-facilitator
  - she gave me meaning in my life with dementia.
- I felt valued and connected
Steering toward new future

- Married Paul – together could steer through troubled water of dementia

- Began to speak out in 1999, but
  - Was I a freak, not representative of others with dementia?
  - I was ready to give up

- Meeting in WA about national program of support groups for people with dementia

- I felt part of this new effort
Towards a new future

- Glenn Rees brought new vision
  - building on efforts of the various States

- **Consumers** of Alzheimer's services
  - alongside family and professional carers

- Consumer Working Group - people with dementia - at 2001 conference
  - Glenn and Robert Yeoh listened to us

- They took action on our recommendations
No longer a mindless empty shell!

- Logo of Alzheimer's Australia changed to give positive and inclusive image of consumers
- We were all working together for improved services and support
- People with dementia part of narrative
- “Living with dementia”
- An ASSERTIVE message
Dementia – national health priority

- Personal stories of those living with dementia appealed to our politicians
- Economic data to back this up
- Parliamentary Friends of Dementia was formed and met with people with dementia, their families and professionals
- Dementia became a national health priority in 2004, a world first
Assertive advocacy ...

- Achieving:
  - Living With Memory Loss program
  - New web site
  - Consumer advice and participation
  - Better services and support

- Younger Onset Dementia Summit

- No longer hiding behind negative image of mindless empty shell

- Speaking freely of what matters
Dementia: disease of society

- Fear prevents people seeking early diagnosis and doctors providing treatment for symptoms
- Fear isolates us from friends and social networks
- We lack support to deal with our cognitive decline and loss of our place in society
- Cures for the many diseases that result in dementia are still as far away as when I was first diagnosed
- No time to lose to change the stereotype, challenge the stigma and fear, and to create dementia-friendly society
My dream: a dementia-friendly society!

- Interventions to modify disease progression are as far away as when I was first diagnosed
- Good social support and care will be needed for the hundreds of thousands of people who will be living amongst us with dementia
- It is up to us, through Alzheimer's Australia, to be assertive in seeking to create a dementia-friendly society in which there is early diagnosis and treatment; and supportive participation in social networks
- We have a strong message and a good story to tell