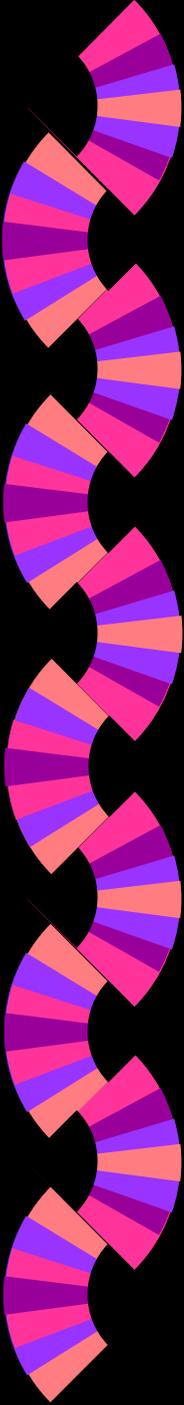


A decade of change

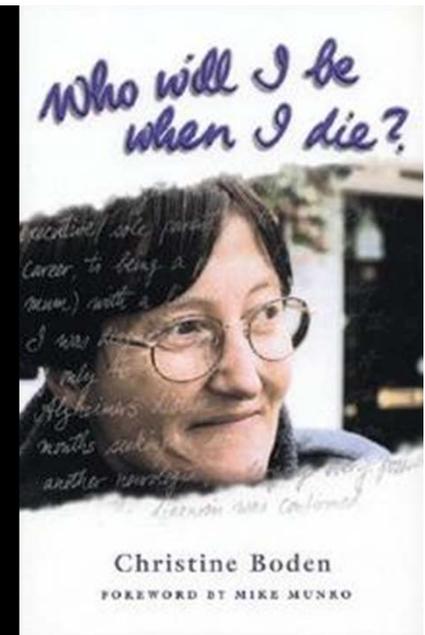
Christine Bryden

www.christinebryden.com



Alone with my fear

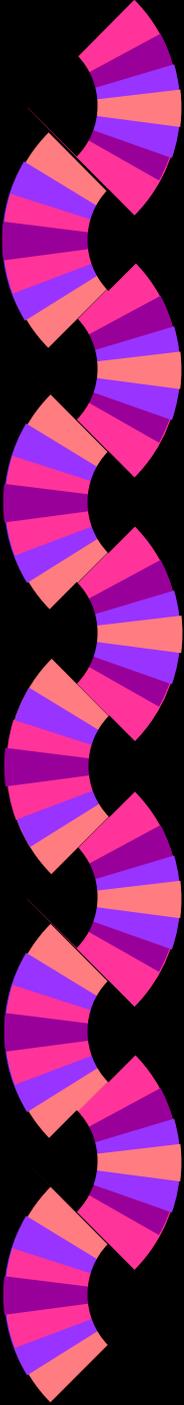
- ◆ Diagnosed 1995 at age 46
 - single, two young daughters at home
- ◆ Life changed overnight, fearful of my future
- ◆ Alzheimer's Australia supported only carers
- ◆ Stereotype of mindless empty shell
 - Would that really be me? How soon?
 - What would happen to my girls?
- ◆ Wrote about my fear **“Who 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**

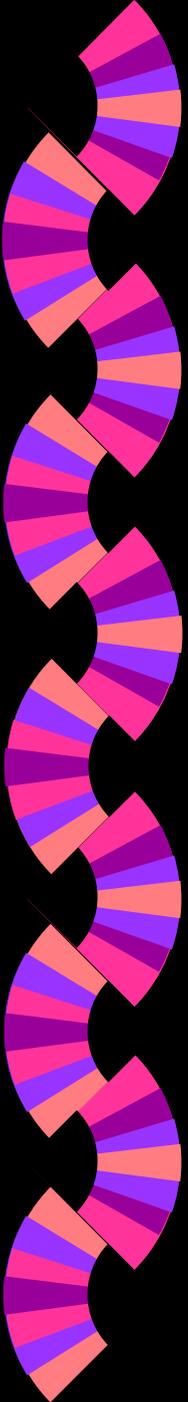




Steering toward new future

- ◆ 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**

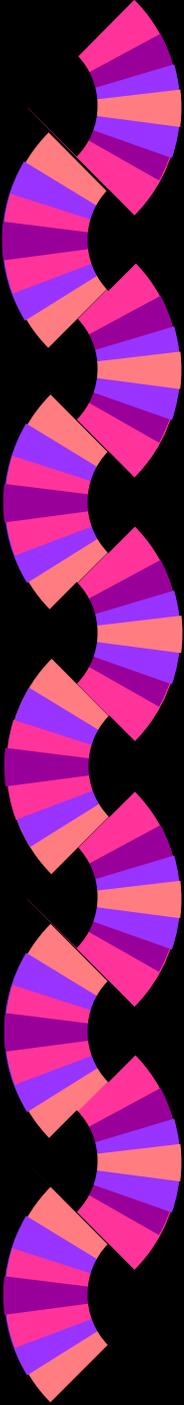




Towards a new future

- ◆ 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

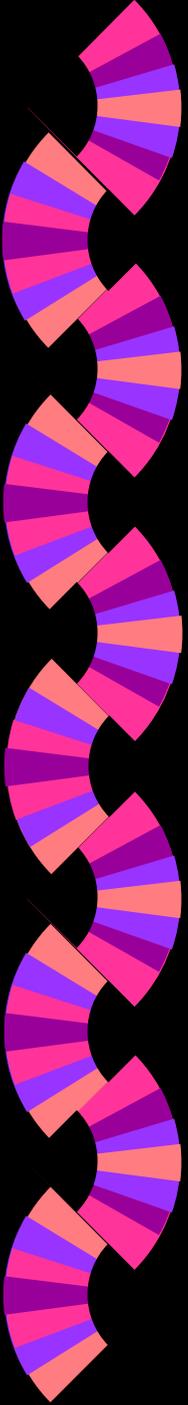




No longer a mindless empty shell!

- ◆ 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

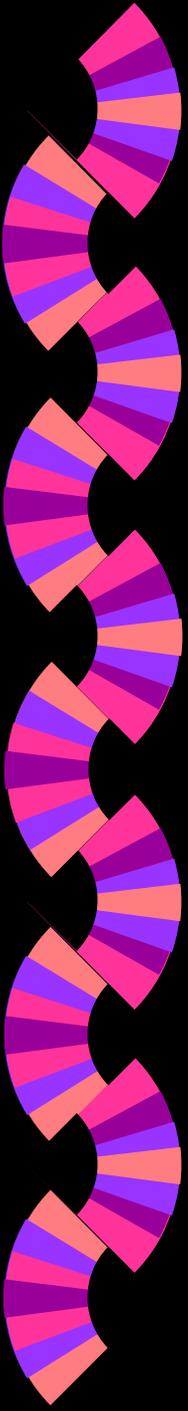




Dementia: disease of society



- ◆ 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