

LAUNCH OF DEMENTIA AWARENESS MONTH IN QUEENSLAND 25 SEPTEMBER

QUALITY DEMENTIA CARE AND THE PERSON CENTRED APPROACH

Many thanks for the invitation to talk today about quality dementia care and the person centred approach.

And thank you to Alzheimer's Australia Queensland for all their support of Alzheimer's Australia nationally. Without the unity and commitment of the state and territories the Alzheimer's family could not exist or achieve what it has over recent years. The work of Jan and her colleagues in creating awareness of dementia and providing services across Queensland is something to be very proud of.

Nor could we do our work without the funding provided through the National Dementia Support Program from the Australian Government. The Australian Government is the principal sponsor of Dementia Awareness Month.

And I thank Pfizer too for supporting the Month for the seventh consecutive year.

Twenty years ago I gave a speech to a conference in South Australia under the title "Only Connect".

Those of you who enjoy good books - or who are my age - may be familiar with EM Forster's writing. If you are, you will know that "Only Connect" comes from that wonderful book "Howard's End" which is about connecting the heart and the mind.

"Only connect the prose and the passion, and both will be exalted, and human love will be seen at its height"

E M Forster experienced the deprivations of a British public boarding school, the intellectual rigour of Cambridge, and then immersion in the warmth of Italian culture and colour. No wonder he understood so well the importance of human connection - of the way we relate to one another as human beings.

I built on Forster's deep insight into the human condition when I gave that long ago talk: The theme of my talk then was holistic care. And achieving that outcome I believe is the challenge that still confronts us in providing the best possible care for people with dementia.

There has been considerable progress over 20 years with the gradual but very real recognition that every person with dementia is different, that we should address the causes of behaviours and not the symptoms, and that attention to emotional well being and a focus on continuing social engagement and preferred activity are critical in promoting quality of life for any person with dementia.

There is much else to welcome. Dementia has been made a National Health Priority and the Minister for Ageing, Christopher Pyne, has announced that the funding will continue after 2009 – a commitment which has recently been endorsed by the Opposition. New initiatives are in place including the first Dementia Extended Aged Care at Home Packages, expanded dementia training programs, increased support for dementia research and the National Dementia Support Program delivered through Alzheimer's Australia.

Alzheimer's Australia can now advocate with even greater confidence for the seven priorities and funding that have been identified in the Dementia Manifesto by the National Consumer Committee of Alzheimer's Australia.

Despite this progress, we have a way to go yet in achieving quality dementia care across Australia, in every sector and for every person with a diagnosis of dementia. So today, I want to talk to you about:

- What Alzheimer's Australia means by quality dementia care.
- The barriers that create difficulties in achieving it.
- Some strategies for improving the quality of dementia care.

Quality Dementia Care

Alzheimer's Australia starts from the position that there is no single or standard approach to dementia care, no "one size fits all" set of practices. The quality of dementia care is however, likely to be high if it is driven by:

- A philosophical approach that emphasises person centred care;
- A partnership approach between the care providers, person with dementia and their family carers;
- A professionally based care environment characterised by strong leadership; and
- Adoption of best care practices that reflect the integration of a clear philosophy, current knowledge and applied skills.

The core principles that underpin quality dementia care include:

- Valuing the work of every person;
- Relating to the person rather than the illness;
- Maximising autonomy, independence and participation;
- Responding to the needs of the whole person;
- Providing an environment and experiences that are enriching and meaningful; and
- A partnership between care providers and family and friends of the person with dementia.

The achievement of good quality dementia care based on these values in practical terms is likely to depend on the organisational commitment of the service provider to the philosophy of care, leadership and environment most likely to support and indeed, promote person centred care.

There remains a real need to embed in our practice, the best approaches in areas such as assessment, training, activities and communication both verbal and non-verbal.

The barriers to quality dementia care

The essence of quality dementia care and the insistence on person centred care may sound like good common sense. In our day to day lives, we all want to be treated as individuals, given due respect and the recognition of our need to share our history and our stories. So why is it that meeting this desire that we all share seems at times to be so elusive and to result in such mixed reports from older people of their experiences of services?

I suggest that it is largely because we have a good system of aged care but not one structured to empower the consumer. Arguably the predominant societal concerns are with security and dependency and institutionalisation.

The aged care sector and consumer organisations for their part, unlike the disability sector, have not usually focused on empowering the individual. They have not sought to vigorously challenge society about the status quo and the value and respect that should be given to the older person who needs support.

To be fair, the aged care sector has emphasised equity more than the disability sector. Funding allocations based on the aged population, and national eligibility criteria, have enabled the aged care sector to provide some level of service fairly evenly across the country. Most aged people can access some support, though this may be far from ideal. Surely it is possible to combine this concern with equity with an approach that recognises and emphasises the individuality of people.

Perhaps the relative lack of interest in the empowerment philosophy in programs serving older people can be attributed to perceptions about whether older people either want or have the capacity to direct their own care.

In respect to people with cognitive impairment or dementia the “malignant social psychology” identified by Tom Kitwood suggests strongly that negative values are attributed to people with dementia and possibly as a consequence to older people more generally.

It is only in relatively recent times that these negative values have started to change with greater awareness that dementia is not a natural part of ageing and with the arrival of Alzheimer’s medications.

It is after all only in the last 10 years that people with dementia have been supported in self advocacy and encouraged to speak out at our conferences and in the media.

And as a society we have yet to recognise that dementia is not only an issue for older people. As a consequence there is a lack of services that reflect the needs of the 10000 people with dementia under 65 with dementia.

Strategies

The central point that flows from reflecting on societal attitudes to older people and people with dementia is that quality dementia care depends not only on the technical excellence of health professionals and care staff and the resources available to them but on strategies that involve the person with dementia and their families and carers in decision making in respect of the care provided.

As a consequence, the strategies I want to suggest for improving the quality of dementia care are of two kinds.

1. Those that enhance the skills of the workforce and increase the resources available to them.
2. Those that enable the person with dementia and their family and carers to be a genuine partner in care decision making.

Specifically the strategies I want to point to are:

- Building workforce capacity and capability
- Dementia specific funding and issues in community care
- Monitoring the quality of care
- Informed consumers and consumers empowered to make decisions
- Advance care planning

Workforce capacity and capability

There is a strong consensus across all the stakeholders in the aged care sector that workforce issues are the most critical challenges facing the provision of aged care services now and into the future. This situation is compounded by concerns about the future supply of informal care.

In response there has been a welcome and increased focus on training, and in particular, on the numbers of nurses and doctors.

But it is not just more doctors we need but doctors who are able to make an early diagnosis of dementia and refer patients to available services including those of Alzheimer's Australia.

Alzheimer's Australia for a number of years has advocated that if early diagnosis is to be the norm, GPs need to be better trained and remunerated, and have improved access to specialists and memory clinics. The issue has been raised yet again in the Manifesto developed by the National Consumers Committee of Alzheimer's Australia for the election. The issue will not go away.

Fear and uncertainty inevitably surround the diagnosis of a terrible condition such as dementia. But it is clear from the stories that people with dementia

and their carers so bravely tell about their experiences, that one issue that can contribute most positively or negatively to their journey is how diagnosis occurs.

In recent months the Department of Health and Ageing has commissioned Urbis Keys Young to undertake a consultancy to look at these issues, including some consultation with consumers. Alzheimer's Australia is looking forward to the release of their findings and the subsequent government response.

In regard to the aged care workforce, there is now increased funding from the Australian Government to train care workers, including in the care of people with dementia.

Alzheimer's Australia has made a significant contribution to this work by developing and getting nationally accredited the dementia component of the Certificate III in Aged Care Work. This component is now compulsory.

More recently, Alzheimer's Australia has just obtained national accreditation for dementia specific training at the Diploma/Certificate 4 level which we expect to roll out next year. There is no comparable qualification currently available.

There are no quick fixes to workforce issues although the National Aged Care Alliance believes a good start would be made if pay and conditions of aged care workers achieved parity with those in acute care.

Dementia specific funding and issues in community care

Since the early 1990s, funding for community packages and residential aged care services has made no special provision for dementia care. Alzheimer's Australia has argued that community and residential care funding arrangements should recognise the special costs that attach to dementia care and in particular for those who have behavioural issues that may affect their care or access to appropriate services.

The decision by the Australian Government to introduce the new Dementia Extended Aged Care at Home packages (EACHD) is a significant advance in recognising the special needs of people with dementia. The packages are funded at a higher level than the highest level of residential aged care funding.

From March next year the new residential aged care funding arrangements will include a dementia supplement.

These are important developments that may improve access to quality dementia care although it is of concern that the aged care industry regards funding for community and residential care as inadequate because the arrangements for indexation do not provide for funding to keep pace with costs.

There has been a welcome expansion of community care in recent years. However, only some 10 per cent of the 40,000 Australian Government care packages are high care (including Dementia EACH). For people with dementia and their families and carers who make the choice to stay at home for as long as possible, access to high care community packages has been clearly problematic.

A related issue is the large gap in subsidy levels between low level packages (CACPs) and high level packages (EACH). This gap makes it difficult for care providers to maintain continuity of care, a continuity that is so essential for the person with dementia. Ideally there should be a continuum of community care subsidies, or at the very least an extra intermediate level, to enable increased care services to be provided by the same service as the person's condition worsens.

The Alzheimer's Australia National Consumers Committee has identified as a priority the need for community and residential care services tailored to the particular needs of those people with younger onset dementia in their Dementia Manifesto.

Monitoring the quality of care

Accreditation, spot checks and the recent measures against abuse in residential care provide some reassurance to older people and their family carers.

Some residential aged care providers believe that since the introduction of accreditation, there has been an improvement in the quality of care. But currently there is no evidence-based way of knowing whether outcomes are improving or not.

Nor are arrangements in place to ensure that the funded bed allocations are implemented, for example in respect of special groups and provision for special dementia units.

The three new Dementia Collaborative Research Centres focussed as they are on dementia care are much needed to produce the evidence needed on best practice in dementia care.

Empowering Consumers

Some of you may have had the opportunity recently to attend the seminars that Alzheimer's Australia held on Consumer Directed Care (CDC) and to listen to the presentation given by Dr Jane Tilly. The objective of CDC is to enable people needing care and their carers to have the option of decision making about the planning and delivery of appropriate services to meet their needs.

Arguably quality dementia care is not going to result if the person with dementia and their family carers are not positioned to have the option of determining for themselves the services they need, and how and when they should be delivered.

While some participants at the seminars felt that there is already a fair degree of consumer choice, in that some care managers and case coordinators currently discuss planned services with consumers and their families, the majority strongly disagreed.

It was encouraging that there was such strong support from service providers for embedding the principle of consumer directed care in aged care programs. Indeed Alzheimer's Australia was pleased in a number of locations to partner with Aged and Community Services Australia and their State/Territory members in organising the seminars, including here in Queensland.

For those who are interested, we have put on our website a report on the consultations which we have made available to the Department of Health and Ageing in Canberra. Essentially, the view of Alzheimer's Australia is that CDC should be embedded in Australian Aged Care Programs.

To make progress we have proposed that three particular options might be considered.

1. Giving the consumer the option of determining their care plans within the framework of Australian Government community care packages including Community Aged Care Packages and Extended Aged Care at Home packages.
2. A trial to be conducted enabling an option for carers to use respite brokerage funds to obtain their own respite care.
3. Giving eligible people the option of a genuine choice between residential care and home based care.

CDC is not in itself a panacea. For example, its effectiveness will depend on good information for people with dementia and their family carers. It will depend on identifying and building up over time alternative service delivery models including greater reliance perhaps on the networks of the person with dementia and their families and carers. This may be of particular value to people from culturally and linguistically diverse backgrounds and to Indigenous people.

The Minister for Ageing has included references to CDC in recent speeches. I hope this signals an interest at the political and bureaucratic level in implementing CDC. Remember there is nothing new in principle: it is where concepts around community options started in the middle 1980s. We just need to do it!

Advance Care Planning

Another priority that the National Consumer Committee of Alzheimer's Australia has identified as likely to contribute to improving quality of life for people with dementia is advance care planning. Advance care planning is important because it allows people with dementia to plan for their future care and financial matters in advance of losing the capacity to make those decisions. Together with an enduring power of attorney an advance care plan

is a significant document that informs health care providers about a person's wishes regarding their health care.

Unfortunately current legal provisions are complex and vary across jurisdictions, terminology is confusing and inconsistent, and all too often the wishes of the person with dementia are not appropriately followed. People with dementia rightfully want to know if the wishes they express will be given effect in a legal document or not. Their quality of care depends on others respecting their wishes. And often it seems to be the case that they are not.

This issue is flagged in the National Framework for Action on Dementia agreed between Health Ministers in April 2006. The Standing Committee on Legal and Constitutional Affairs in the House of Representatives will make recommendations soon on older people and the law. Hopefully some political initiative will result that gets the complex and difficult issues in this area properly examined and acted upon including better information provision for people with dementia and their families.

Conclusion

We have a way to go in achieving a good general quality of dementia care. But there has been great progress over the last 20 years and it is clear that people with dementia and their family carers know what is needed to do better. The Dementia Manifesto sets out clearly the agenda that can help to achieve this over the life of the next Australian Government.