

WHAT'S BUSINESS WITHOUT CHANGE? BRING IT ON!

**AGPN NATIONAL FORUM
TRANSFORMING FOR SUCCESS – BUILDING ON STRENGTHS,
EMBRACING PARTNERSHIPS**

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I am pleased to have been given this opportunity to speak at this important conference and thank the AGPN and Leanne Wells for inviting me here.

It is so important to consider the issues that you have before you in health and care reform from the perspective of consumers and not just on the basis of the financial issues that so dominate these debates.

I have a passionate interest in ageing and dementia.

I have developed some strong views as a former carer for my father and as a consequence of the roles I have carried out over recent years with arthritis Australia and the macular degeneration foundation, and more recently as national president of Alzheimer's Australia .

I have been invited to talk to you today about challenges to the health care system over the next few decades... From a consumer perspective.

Much of what I say this afternoon is coloured by the family carers and people with dementia that I have met in the last six months. And more recently by the moving stories we have heard over the last three weeks when Alzheimer's Australia took part in consultations across Australia on the reform of aged care.

Alzheimer's Australia was funded by the department of health and ageing to undertake these consultations on recommendations of the report of the productivity commission report caring for older Australians.

But the challenges faced by those living with dementia are not constrained just to one part of the system or another, and not surprisingly, consumers have wanted to talk about much more than just aged care.

They have wanted to speak about the whole experience of the journey of dementia.

These discussions have given us insights into how the care system works; how important a diagnosis is to planning the journey with dementia and the difficulties of navigating the system.

There have been some good stories but we have heard many more heart-wrenching experiences.

And it is clear to me that consumers want two things above all.

First, they want to be empowered as active partners in care planning and services... People with dementia and their carers want to understand the process and the decisions before them, and they want to be able to exercise some control over the care and the services they receive.

And secondly, consumers want an integrated care system with clear pathways of care.

Right now the system fails to deliver either of these things to most, and it is the nature of these failures, and the things that might be done to address them that I am going to focus this afternoon.

For most people with dementia – and certainly for my own father who had vascular dementia – the journey starts with primary care.

We know from market research that 94 per cent of people who are concerned about their memory will consult their gp as the first point of contact.

This shows that, as with many other chronic diseases, people experiencing the first symptoms of dementia know where to access the system for information and services.

Unfortunately, the relatively straightforward entry point belies a confusing maze of aged care team assessments, uncertainty about diagnosis, and uncertainty about how to manage the disease.

Alzheimer's Australia recently conducted a review of different national plans in Australia and other countries to address dementia. There is a common theme to these different plans.

The same approaches that are used to tackle other chronic diseases such as cancer are the ones that are needed to address dementia, and are essentially the gold standard of any public health framework. They include

- Risk reduction
- Early diagnosis
- Disease management
- Palliative care at end of life
- Appropriate investment in research

Few would argue with the logic behind this framework, but remarkably, dementia is often not seen as a chronic disease at all. Rather, it is often considered an unfortunate consequence of ageing.

Dementia is not a normal part of ageing.

We are facing a dramatic shift in the prevalence of chronic diseases in Australia. Whereas prevalence rates for diseases such as cancer and heart disease are beginning to stabilise, dementia prevalence continues to increase.

Without a medical breakthrough, Australia is facing the near certainty of almost 400,000 people with dementia within 10 years, over half a million in 20 years, and close to one million people by mid-century.

This is very simply a function of the ageing population – something that I do not have to explain here – and the fact that in spite of a global research effort, there is still no prospect of any treatment to halt, delay, or cure dementias such as Alzheimer's disease.

Alzheimer's is the most common form of dementia and accounts for 50 to 70 per cent of all cases.

The pandemic is coming. And first in line to feel its impact will be our health and aged care systems.

By 2030 expenditure on hospitals and residential care for people with dementia will be the third highest cost – and by 2060 the largest.

Perhaps because of this, so much of the health care debate has been concentrated on how services will be funded rather than on meeting people's real needs for care.

The productivity commission report into caring for older Australians was refreshing in that it focused on providing consumers with greater access to the care they need and how where they want to receive it.

Looking across chronic diseases and the ageing of the population, I feel there are six key areas that need to be addressed going forward. These are:

1. Empowerment of consumers
2. Consumers knowing where to go to get the services they need
3. Services and professionals that are integrated and communicate
4. Preventative health
5. Workforce
6. Quality care at the end of life

In terms of empowering consumers of health services, there has been an increasing awareness in the health community of the importance of partnering with consumers in developing care plans and working together to address chronic disease.

The consumer health forum of Australia has played a key role in raising the bar in terms of ensuring the consumer voice in the health care system. But there is still much to be done.

We have heard countless stories of families who *knew* something was wrong but had their concerns downplayed or dismissed by their GP as "just a normal part of ageing".

Let me repeat something I said earlier: dementia is not a normal part of ageing. For many people, such a rejection will mean a delay of several years in getting access to a diagnosis; years that will be filled instead with untold stress and worry about what is going wrong.

In a disease as difficult to diagnose as dementia, families must be partners with the GP from the start.

Unlike diabetes or some of the other chronic diseases, there is no single test that provides a definitive diagnosis. The family member who has lived with the person for the last 30 years is most often the key to a timely and accurate diagnosis.

Empowerment is not just about diagnosis but it is also about having real choices about care. Most older people with or without dementia want to stay in their homes and their communities for as long as they possibly can. I certainly do, and I am sure that most of you – if not all of you – would not wish to spend your final years in a nursing home if you could avoid it.

But as one person who was at our consultations said: “there is a great need for services that suit clients and carers, not just providers.”

It is absolutely essential that in future the journey through the system is more geared to the needs of the patient rather than the system. Dementia is a confronting diagnosis and the path through the system must be easy for the person with dementia and their family carers to navigate.

There is a need too, for more community services and especially respite care. But in the health reform process there was hardly a word about the role of community services and doing more to invest in low cost services that do so much to improve the quality of life of older people and their family carers. Indeed it seems to me that aged care reform is last cab off the rank in health priorities.

For many knowing where to get services can be a challenge. “travelling through muddy water”... “a complicated maze”... “the system is complex and mysterious”

These are just some of the words that people who had talked to us have used to describe the health and aged care system. There is no shortage of information. Many consumers told us of the piles of pamphlets and brochures they had received. But they still did not know where to go to get the services they needed.

For people from multicultural backgrounds the problem becomes even more difficult.

People also feel that they are shoved from one service provider to another with no one to guide them through the dementia journey.

Perhaps even more surprising is that some consumers who have worked in the health care sector find accessing information and services to be a confusing web of phone numbers and referrals.

Of course, in an ideal world, we would be able to straighten out the maze and we hope that the reform process will achieve this to some extent, but we also realise also that the system is complicated and these things take time.

So as part of the reforms, we need to assess whether the new “gateway” recommended by the productivity commission has the potential to bring together assessment, information and ongoing support.

In the implementation of this new concept it will be important to build on existing networks established by community-based agencies such as council of the ageing,

carers Australia, Alzheimer's Australia. In some regional areas that we have visited these networks seem to be working well for many people.

Whatever happens we must ensure that the new "gateway" is not simply a path to more pamphlets and phone numbers but a strategy that results in people accessing the services they need at different stages of their journey.

Consumers say they want to talk with someone who can guide them through the system. In our consultations a number of consumers raised the need for a "key worker" or a "dementia link worker" who could work with individual families to support them through the maze and assist them in finding out where to get services.

This model has worked well in breast cancer, with specially-trained and registered breast care nurses acting as patient advocates and assisting in coordinating care for women with breast cancer, their families and carers.

People who have been affected by breast cancer say the coordination and support services of these nurses have made a huge difference in their journey. And in designing a new world it will be important to consider the role that Medicare locals might play.

Throughout the dementia journey, people may need services from their GP, practice nurses, neurologists, geriatricians, psycho-geriatricians, neuro-psychologists, aged care providers, allied health professionals such as speech therapists, occupational therapists, diversional therapists, palliative care specialists and so on.

You can imagine that having to tell each of these individuals the history of the person with dementia is challenging. Filling out endless forms with the same details every time you have an appointment is maddening.

For example, one consumer said "once my partner entered the system I would have thought that medical professionals and care facilities would be consulting with each other but this is not so. The amount of paperwork that carers have to deal with is complicated, stressful and emotionally draining."

We look forward to the electronic-health record which should ensure that information about a patient is shared across health care professionals.

At the same time, we must not forget the importance of face –to-face contact and discussion about the care of a patient.

A GP doesn't treat the patient in isolation. There is a need for a holistic approach that considers how all of the professionals can work together to support the person with dementia.

Usually, the journey with dementia is a long one, often over eight to 10 years! It requires a partnership between the GP, the patient, the family and a host of services: community aged care services, home and community care (HACC) services, Alzheimer's Australia's *living with dementia* courses and their wealth of information for those with dementia and their families; plus the dementia behaviour

and management advisory services (or DBMAS)...they're just some of a GP's allies in helping people with dementia and their families.

Now if any of you are sitting there a tad confused about what is available imagine how a person with dementia feels!

The divisions of general practice – or soon to be Medicare locals – and the colleges of general practitioners should be providing all GPs up-to-date information on what services are available.

One of the commonest comments from consumers is their concern about lack of, or delay in, diagnosis.

GPs should consider the importance of cognitive function in the same way gps are diligent in checking blood pressure or for breast lumps.

Cognitive testing is particularly relevant if there are any complaints of memory lapses and for older patients, for example in the 75+ assessments. If time is an issue, and it usually is for GPs, properly trained practice nurses could carry out rapid testing and discuss results with the GP.

One of the positives I have seen in the recent health reforms has been an increased focus on preventative health something I fervently believe in.

The development of the new Australian national preventative health agency signals that government is taking seriously the need to keep people healthy instead of just focusing on curing people who are already sick as a priority. The new health agency will initially concentrate on obesity, tobacco use and harmful alcohol consumption. My concern is that most Australians are unaware that there is a link between physical health and brain health. The same things that we can do to keep our heart healthy may also reduce our risk for dementia.

Given that dementia is the second most feared disease after cancer, and among older Australians the most feared disease of all, it is negligent to not make use of the links between these diseases.

There is now evidence that approximately half of the cases of Alzheimer's disease worldwide are potentially attributed to risk factors such as diabetes, hypertension, obesity, smoking, depression, cognitive inactivity and physical inactivity.

Alzheimer's Australia is working to forge new partnerships to address some of these common risk factors. We are part of a consortium representing the heart foundation, national stroke foundation, diabetes Australia, kidney health Australia and Alzheimer's Australia.

Together, this group recently wrote to the minister for mental health and ageing, mark butler, about the need to include assessment of the vascular risk factors that may lead to so many chronic diseases as part of primary health care checks.

Together with the BUPA health foundation, we also recently released an iPhone app- “Brainyapp” which aims to increase public awareness about the risk factors for dementia.

More than 85,000 Australians downloaded this app within five days – making it Australia’s most popular app – and pointing both to the level of interest in dementia among the population, and to the level of demand for risk reduction measures.

One theme that emerged over and over again at our consultations – and one that might surprise you – is the need to invest in our health workforce.

Consumers are keenly aware that quality health services are dependent on a workforce that has good pay, access to training and up skilling, and a career pathway.

Access economics has estimated that the shortfall in the community and residential workforce for people with dementia will be around 150,000, both informal and formal carers.

There are problems too for the care of people with dementia in the acute care sector which perhaps receive less attention.

Often people with dementia are not recognised as having cognitive impairment when they enter hospital and as a result, they do not receive appropriate treatment.

One consumer told us of her mother being asked to tell the doctor which hip she had broken. Her mother was in severe pain but was unable to communicate and the doctor’s questioning just made the situation more confusing.

Other families tell of how they are asked to provide personal care to the person with dementia because the staff is just not trained to do so. One consumer in Melbourne said “there is no staff training about dementia in hospitals. If I didn’t go in to feed my father he wouldn’t have been fed for two weeks.”

My own father was in and out of hospital in the last 12 months of his life and I always had to explain to nursing staff the needs of someone with dementia.

“Your father has been behaving in a very agitated way” a nurse told me, crossly. This was not an isolated complaint. It happened many times.

I used to explain that when the routine of someone with dementia is interrupted they become confused, agitated and sometimes aggressive.

“Your father didn’t order his meals,” a nurse complained on another occasion. “He can’t see to read,” I told her. “He has macular degeneration.” His condition was noted on his chart but she had failed to read it or didn’t know what macular degeneration was...

And when he was in the last week of his life and he needed help to eat, his hospital told me they didn’t have anyone available to feed him his meals. Couldn’t I arrange

for his carers and family to come in and do that. Dad had had health insurance from the day it was first introduced....

He was always cold too. In whatever hospital he had the misfortune to be in. It's my experience that older people are often cold.

If I can digress for a moment...I'll never forget the Christmas eve I took the kids up to have afternoon tea with dad at his home in Sydney's north shore. He was waiting for us in the lounge room, sitting before a blazing log fire.

It was about 32 degrees outside. "Dad, what's with the fire?"

"I was cold," he said. Right! So we had afternoon tea in front of the fire on one of the hottest of summer days...it was a memorable Christmas eve.

These anecdotes show how urgently we need to increase the level of understanding and skills in dementia care across the sector.

We need to ensure that the health work force is prepared and trained for the changing pattern of chronic diseases that the ageing population will present.

With the growing number of older people in Australia it will be increasingly important that some member of a group practice have experience with geriatric issues and seek out training on dementia diagnosis and management. Quality care at the end of life will also be essential.

GPs and other health care professionals have the difficult responsibility of caring for people at the end of their lives.

The advances in medicine and medical expertise over the past century have given us unimaginable increases in life expectancy and improved population health on many levels.

However, death is also a part of life, and there will come a time for most when the care paradigm will need to shift from preventing or curing disease to ensuring a quality death that recognises and respects an individual's choices, and caters to their emotional and spiritual needs.

Unfortunately, relatively few people with dementia experience quality palliative care.

End-of-life complications such as infection and anorexia are often treated as medical emergencies that prompt hospitalisation, rather than as normal end-of-life process that can and usually should be managed by general and specialist palliative care teams in the person's own home, or nursing home.

Pain in people with dementia is also dreadfully mismanaged.

A person who cannot tell their doctor where it hurts or how much, is less likely to receive appropriate analgesia, and is more likely to be sedated or restrained. Yet

almost all people with dementia do experience moderate to severe chronic pain, and almost all should be prescribed regular pain medication.

It is also vitally important that health care providers encourage and assist people with dementia to engage in a process of advance care planning early on.

This is difficult of course. Just coming to terms with a diagnosis of a terminal illness such as dementia and the huge implications that this will have for a person and their family is difficult enough, without having to also think about treatment options that may or may not be relevant years in the future.

Yet these decisions and the process of making them are vital to help reduce more heartache and grief later on.

Let me read a quote from one of the consumers we spoke to recently:

“My mother passed away last year. We looked after her at home until she was very ill.”

“After entering the nursing home it was extremely undignifying. She couldn’t swallow, lost weight, was less than 40 kilos, lost her sight.

“I am still feeling that I let my mother down. She used to say ‘you will know what to do’ ... presumably sleeping tablets.

“When my turn comes I have requested palliative care. I don’t want my grandchildren to see me curled up with contractions.”

“I wake up at night thinking about it. My mother’s wishes were not taken note of.

“I had to plead that mum would not be taken to hospital in ambulance. They were giving her antibiotics to keep this poor lady alive.”

I am not here today to speak about voluntary euthanasia, although it is a debate I believe that this country needs to have. And it is a debate Alzheimer’s Australia has set out to inform.

However, I do want to stress that allowing a person to die in comfort, free of pain, and surrounded by friends and family often does constitute best practice care.

Removing them from their family and surroundings to send them to hospital for aggressive antibiotic treatment, tube feeding and artificial hydration, often is not.

So where to from here?

I have outlined for you some of the main areas of the health care system that, from a consumer perspective, need to be changed. My focus has been on dementia and aged care but I am sure many of the same issues cut across all of the other chronic diseases.

But what are the opportunities to create change?

The establishment of the Medicare locals presents a real opportunity to rethink how the health system works. Consumers question whether we really have a “system” now or just a number of different services and professionals that aren’t working together.

The idea of the Medicare local has promise. An organisation whose goal it is to integrate services and make it easier for patients to access the services they need by linking GPs, nurses, hospitals and aged care and which has responsibility for identifying gaps in services in local areas sounds excellent.

But the challenge of course is in implementation. How do we achieve an integrated system that responds to the needs of individuals?

I am heartened to see that some Medicare locals are already taking up the challenge of finding innovative ways to communicate with consumers.

A new Medicare local here in Melbourne has developed a blog where members of the community can share ideas about how health care could be improved in their community.

A second requirement for change in any business environment is changing attitudes and culture. There needs to be a shift in thinking about diseases that are associated with ageing such as dementia that moves our political and professional awareness from seeing them as just a part of growing old to being the major chronic diseases of our time.

We can not delegate the care for people with dementia to the aged care system, although the system obviously does have a very important role.

Instead we need to recognise that the same principles of risk reduction, timely diagnosis, good management, and palliative care that apply to other chronic diseases are needed to address dementia.

We need to move from a system which focuses on “curing” individuals who are sick to one which aims to keep people well and enables them to achieve the best quality of life regardless of any chronic disease they may have.

And, as part of this change in culture, we need to embrace a shift in the power relationship between patients and their doctors.

As consumers become empowered through greater access to information, they will demand a greater role in their care planning.

Already doctors have patients coming into their offices with research articles under their arms. As the baby boomers reach their 70s and 80s, I can assure you that this trend will continue.

Technology will also provide opportunities for new ways of providing good access to care for people in regional and remote areas.

There will be exciting new possibilities with telemedicine by virtue of the nbn. We also have prime opportunities to improve continuity of care, coordination between care providers, and transparency for the patient through the new e-health records system.

But we must also ensure that the important relationships and communication that occurs face-to-face between health professionals and patients are not lost.

Ladies & gentlemen: there are a number of exciting activities that Alzheimer's Australia has initiated to try to address the concerns about diagnosis and the management of dementia in primary care.

We are looking at ways to incorporate information about dementia and referral services into medical director, which as you know the leading software used by gps in their practices.

The idea is simple. We know that GPs have limited time so we want to make information about dementia available at their fingertips.

At a press of a button they will be able to print out fact sheets for patients including information about support services through Alzheimer's Australia and other agencies or letters of referral to specialists.

In addition, we would like to incorporate a reminder that would pop up for patients over a certain age, for the doctor to ask questions about memory and thinking. Last year, Alzheimer's Australia put a proposal to the government to bring together the major stakeholders in primary care for a national seminar to discuss ways to achieve timely diagnosis of dementia.

As a starting point Alzheimer's Australia subsequently released a publication "timely diagnosis of dementia: can we do better?" Which provides evidence about the length of time until diagnosis and outlined the major barriers to getting a diagnosis. We have again included this modest proposal in our budget submission for 2012. Timely diagnosis is one of the priorities that consumers have identified for the national quality dementia care initiative which is a program that aims to improve the quality of dementia care by getting research into practice.

We are currently reviewing a number of applications to this program which have come up with innovative ideas about how to improve diagnosis for people with dementia across Australia. We expect to announce the successful grant recipients in mid-February.

In closing let me say that I hope that the health care system we see in 10 years will be significantly different than the one we are familiar with today.

I am hopeful that we will have a system that empowers consumers and which provides an integrated system of care.

What's health care without change – from a consumer perspective? I say: bring it on!