Slaying the Dementia Dragon: Speaking Notes

Alzheimer Australia 12 May 2011

SLIDE 1: TITLE

Thank you, Chairperson. Good morning everyone. What a wonderful honour it is to be here and receive the warmest of Australian welcomes. My sincere thanks to Alzheimer Australia, Western Australia and in particular to Frank for the invitation to come here and be part of this great event.

I am privileged to stand before you this morning; privileged to have worked with the Alzheimer Society of Ireland for the past 7 years and to be part of the Alzheimer movement; many of you here today also share in this privilege – being a part of the movement, providing services and supporting people with dementia to have their voice heard. However, I think this is perhaps where the privileges end. The reality of living with dementia in this the 21st century is far from being privileged. We all know that the stigma and social exclusion associated with dementia impacts hugely on the lived experience for both the person and the carer. And it is these very themes that I explore in more detail with you this morning.

The title of my presentation is ‘Slaying the dementia dragon: Alzheimer organisations responding to stigma and social exclusion’. My contention is that stigma is the dementia dragon and that Alzheimer and other support organisations have a pivotal role to play in addressing it. I am very aware that while some of you here today are involved in Alzheimer type
organisations many of you are not. Well don’t you worry because, what I say to you this morning has universal application. In fact I am pleased that there is a mixed audience here today because addressing stigma and social isolation is not something that can be tackled single handedly – it is a multi-layered, complex issue needing systemic and societal solutions with all of us actors playing their part. Today, I am not going to blind you with facts and figures, bar charts and pie charts. Instead where I am coming from is a much much more primal place, based on learning, reflection, reading and probably most importantly listening to what the range of actors on the stage are saying about this challenging subject and in particular what people with dementia themselves are saying.

Before I proceed any further, I wish to acknowledge that the dragon image you see on the slides is taken from one the covers of Terry Pratchett’s books, world renowned author who has Alzheimer’s disease. And I have a confession to make. I have not sought his permission to use the dragon but I have no doubt that he won’t mind me using it in this way.

NEXT SLIDE

SLIDE 2: OVERVIEW

In order to understand the phenomenon of stigma in dementia and the social exclusion that it results in I will briefly explore the issue itself, frame the challenge that it presents and explore how we may find the solutions to the challenge. Whilst stigma is a much talked about phenomenon in the world of dementia perhaps it is time now to take stock and really examine what is being said, who is saying it and what is being done. Today I pose lots of questions so that we may somehow together arrive at the answers we need.
Dementia stigma is not a new phenomenon. It is actually centuries in the making. The word ‘dementia’ as many of you know, is taken from the Latin word *demens* which means ‘without a mind’. Stigma is an entirely socially constructed phenomenon. One of our own making. So our understanding of dementia is firmly rooted historically, socially and culturally. So if, as we are, wanting to change the course of history and societal culture, I am certain you will agree that we taking on a significant challenge! I know there is a deeply held appreciation among the people sitting in this room that the stigma associated with dementia is a result of how it has been constructed, how this construction is interpreted and indeed how it is played out in everyday life. Dementia may well be viewed as the ultimate badge of shame. Research carried out by ourselves in the Alzheimer Society of Ireland on perceptions of stigma in dementia describes dementia as a ‘dark place still’. It found that stigma was embedded in people’s overall experience of living with dementia. Because of the stigma, people are either choosing to or being forced to live ‘behind closed doors’.

So as you sit here this morning, try to image, just for a few moments, because of something organic going on in your brain you are no longer deemed by others to be socially acceptable. You are singled out for your stigmata. Your participation in the normal everyday activities is no longer an option in your life because of the way that people perceive you and how we as a society respond. Your friends gradually pull away and your life becomes one of endless limits and rejections. Try to imagine the impact that this would have on you as a human being. Do you think you would feel
devalued? Demeaned? Isolated? Worthless? Try to image the impact it would have on your family? In reality do you have you any power to change it?

NEW SLIDE

SLIDE 4: KITWOOD RECONSIDERED

But let’s begin to scratch a little deeper into the meanings of dementia; what is really going on to ascribe dementia the status it has in society? In the end, there was only one place I returned to try to find the answer and that involved revisiting the seminal work of Tom Kitwood and really just getting just getting to basics.

Productivity and individualism are highly valued in Western societies. These values automatically reduce those with significant disability into the exclusion zone. Writing in the mid 1990s, Kitwood argues that the time has come to readdress this balance to recognise ‘men and women who have dementia in their full humanity’ and have the human being recognised as a person rather than an object. In his book, Dementia reconsidered: the person comes first Kitwood drills down to identify and find the ‘person’ with dementia and in so doing he provided us with the foundation for understanding the philosophical basis of a person-centred dementia care model. In his analysis to develop the model he addressed two essential elements. Firstly and vitally, he was involved in engaging in a dialogue regarding the longstanding issues of the stigma associated with cognitive impairment and secondly he involved himself in examining core western
societal values. Kitwood examined the traditional perspectives of people with dementia and argued they devalue the person and make ‘a unique and sensitive human being into an instance devised for convenience or control’. We devalue the person because our conventional thinking and set of beliefs are that rationality, productivity, autonomy and individualism are the most valued elements and ascribe status in society.

Essentially, he is asking us to reconsider dementia as an invitation to a fresh understanding of what it means to be a person. The emphasis on individuality and autonomy is called into question and the reality of us as interdependent and relational social beings comes to the fore.

NEXT SLIDE

SLIDE X: QUOTE FROM CHRISTINE BRYDEN

So what does this all mean for the person with dementia? The words of your own Australian Christine Bryden are really useful in translating what Kitwood’s theory really means and helps us to really understand the reality of living with dementia: She says “How you relate to us has a big impact ............You restore our personhood, and give us a sense of being needed and valued. Give us reassurance, hugs, support, a meaning in life. Value us for what we can still do and be, and make sure we retain social networks. We’re still here, in emotion and spirit, if only you could find us.”
Slide 4: WHY THE DEMENTIA DRAGON?

So why do I refer to stigma as the dementia dragon? Well there are a few key reasons. Unlike many other conditions and diseases, dementia carries with it some unique elements. There is no cure. Treatments, at this point, have minimal impact; the nature of the condition, in and of itself, resulting in a decline in cognition and the ability to control your life is massively fearful for us all. We know from research that when the diagnosis is made very often the person sees it as their own fault, internalises it and begin to struggle with a sense of shame and inadequacy.

Agnes Houston from the Scottish Dementia Working Group talks about the reactions she experienced when she told others about her diagnosis. These reactions went from denial to rejection. To quote Agnes “I started to be very careful about whom I told I had dementia. I started to say that I had a cognitive impairment. It seemed more socially acceptable, with no stigma attached and no preconceived ideas”. Agnes goes on to say “by hiding our diagnosis we help to create the stigma. We are ashamed of the condition”. Yet the burning question still remains for me, why the shame, why the fear? I have come to the conclusion that it is a vicious cycle really; as a people, we have socially created particular meanings of dementia which makes those with the condition ashamed of it and this in turn becomes the lived experience. It starts again and so it goes, on, and on and on. So, if you are living with dementia the stigma factor is the ever present dragon in your life.
Next slide

Slide 5: SLAYING THE DEMENTIA DRAGON: THE CHALLENGE

(CLICK) If we look at framing the challenge, we know that stigma impacts at many different levels and in many different ways. Upon diagnosis, the person with dementia is ascribed to a new social group. (CLICK)

This social grouping is characterised by increasing exclusion, isolation, discrimination and often mistreatment resulting in a life lesser lived. (CLICK)

In addition, family members and those of us who work in the dementia workforce experience stigma by proxy. Joe English, one of our members who has dementia summed it up very nicely recently by saying: “everything has changed so you have to create a whole new world around it”

(CLICK)

An additional consequence of the stigma is the delayed diagnosis and often the non-disclosure of the diagnosis. Very often there is a dismissive response from health care professionals. In many countries, there is limited access to specialist care and relatively poorer quality of care than for other conditions. There is inadequate investment and lack of a commitment of resources to dementia service provision. Dementia is then marginalised within the health care system and not seen as a health priority. (CLICK)

Finally we witness a lot of misconceptions and a wholly negative attitude in the public arena in relation to dementia. So you can see the vicious cycle emerging before your eyes. But we can break the cycle and this is our challenge.
And so that brings me nicely to framing the solution. (CLICK)

In the centre I have placed the Alzheimer organisation as the leader in taking action as I believe we are key to the solution. (CLICK)

Central to the solution to slaying the dementia dragon as it is currently constructed is engaging people with dementia and their carers. I will refer to these two key tools in more detail later on. (CLICK)

If we are prepared and ready for action we will then be able to tackle the broader issue of stigma among the dementia workforce and health care professionals in particular. (CLICK)

In turn then we will begin to tackle the health system and increase the prioritisation of dementia within that system. (CLICK)

We also have a role to play in changing the meanings of dementia in the broader public arena. (CLICK)

Finally, this will lead to the active citizenship of the person with dementia, the antithesis of the social isolation of being stigmatised. We will have achieved our ultimate goal of breaking the cycle, enabling people with dementia to be active citizens and having dementia as part of our everyday lives.
SLIDE 7: ALZHEIMER ORGANISATIONS INNOVATORS OF CHANGE

Let me get back to the role of the Alzheimer and other related organisations as I said I would: while we may not be able to be everyone’s ‘knight in shining armour’, we can be innovators and leaders. I would argue that there is a moral imperative on Alzheimer and related organisations to take action. Who else is going to do it? PAUSE. So let’s take responsibility and ownership of the issue and crucially let’s decide what we can do and cannot do in order to assume a leadership and innovation role. Let’s turn the key and open the door.

SLIDE 8: WHAT PEOPLE WITH DEMENTIA ARE SAYING ABOUT US

As I say our organisations are imperative to the solution but at this moment in our history what are people with dementia saying about us? I quote them directly:

“Why do I play this exhausting game of hide and seek? Is this my problem alone or is it also yours?”

“For better or for worse the world depends on the people seated in this room to make it right for people living with dementia”

“We look for leadership from our leaders, from our Alzheimer societies to do more than raise money for research. We look to you to provide more than information, group experiences, places to store us for a day. Why don’t you do first things first: directly support people with the dementia in whose name you raise money?”
SLIDE 9: FELLOW TRAVELLERS

As organisations attempting to provide leadership in this area the most crucial asset that we have are people with dementia – they are the KEY TO CHANGE. Therefore there must be a clear sense of SOLIDARITY in our organisations that we are walking the journey with our fellow travellers. We must engage people with dementia in all aspects of our organisation; we must listen and learn; we must provide understanding and put in place what is needed to support people to have their voices heard. I would argue that there is an ethical obligation on the Alzheimer movement to become inclusive of people with dementia. Indeed there is strong evidence to show that where there is direct contact with the person with dementia the stigma is greatly reduced. We have amazing means of communications now and we can reach out to and link together new generations of people, including our fellow travellers.

Stephen Post is a US based Ethics professor. He argues very strongly the need for moral solidarity in that we must recognize the essential unity of all human beings, despite differences that may be present in their mental capabilities. He strongly reject the current casting aside of the person with dementia and their unworthiness in terms of social, moral and political protection. As a society, we must work together to ensure that those with dementia are respected and supported to live meaningful fulfilled lives. We so often hear that nothing can be done about dementia but Stephen Post argues very differently. He says “Solidarity, comfort and reassurance are not “nothing””. We are all in the same boat and there can be no empirically
determined point at which it is justifiable to throw some people into the sea.’

**NEXT SLIDE**

**SLIDE 10: WHAT IS YOUR DRAGON?**

But before we can walk this journey together we need to examine ourselves and see is there a dragon inside us! Are we ourselves nervous and fearful of people with dementia? Are we embarrassed and somewhat ashamed of being a member of the dementia workforce and the Alzheimer movement? Is there a need to identify our own prejudices and face our own human fears? At the very least I am suggesting that must be-friend our own dragon first. *(CLICK)*

This will enable us to internalise the beliefs and attitudes to ensure we value the person with dementia and their power as change agents.

**NEXT SLIDE**

**SLIDE 11 VALUING PEOPLE WITH DEMENTIA**

At this point, I think it would be interesting to revisit what people with dementia are saying about their worth and value to the Alzheimer movement. Again I quote their voices directly:

“We do not bite. We may sometimes need an explanation; we may need to be told several times, we may get confused in ways you are not. But does that mean we should not be full partners with you in our crusade?....Let us in! Affirm our worth by partnering with us”

“Only those living with dementia know what it is really like..........let us cease to be a sideshow and instead become full participants in the work”.
Slide 12: CHECKLIST FOR ORGANISATIONS

If we really believe in the value and power of the person with dementia, as organisations working with people with dementia, I think there are a few questions that we need to ask ourselves. How would you answer the following check list of questions?

- Do the staff/volunteers/people with dementia in our organisations feel stigmatised?
- Are we ourselves as organisations and health care professionals unwittingly serving to stigmatise and isolate people with dementia?
- Are we learning from what we have already done and auditing those experiences?
- Are people with dementia involved in our organisational structures? Are they represented on our board of directors? Are they on our committees? Are they part of our volunteer corp?

I would argue as organisations we need to address these issues and develop an organisational culture of person-centeredness for EVERYONE.

Slide 13: FROM THE INSIDE OUT

Change is from within. We need to change from the inside out. We need to change as people; change as organisations and change as a society. We know there is a need for multi-level changes which takes time. Don’t let our impatience hinder this. Leadership and innovation will show us the way.

In the way that people with dementia needs cues in their lives we need cues to be different. We need to have messages and constant reminders of what
we are trying to do. Let’s stand out from the crowd and be different. Clearly Alzheimer organisations cannot do this work alone. We need to work together with others to make it right. Let’s be the champions.

**NEXT SLIDE**

**Slide 14: WHERE TO FROM HERE?**

Earlier on I talked about how we got to this point in our history, but what we need now is a clear vision for the future. **Where do we want to go to from here?** We need a set of directions and if we are wise we will construct a good roadmap. But what does this roadmap look like? We have an opportunity now to construct this map. A good place to start is to take stock of the current map and how it is constructed.

- What are the current conversations and dialogue around stigma and dementia saying? Or in actual fact, is there a dialogue at all? If there is, are there new ideas emerging? Who is leading the dialogue? **And who should be leading it?**

- Should we demolish the existing meanings and understandings, reconstruct them and ascribe a new set of meanings to what we know as dementia?

- Do we need rights based principles to permeate the conversation?

- Do we need to create a discourse and dialogue about dementia as a socio-economic and political issue and move it into other frames in addition to the medical one?

We as Alzheimer and related organisations, people with dementia, carers, health care professionals and academics need to create a safe space for debate, discussion and reflection and push out new meanings and conceptions of dementia. Together we need to vision the future we want; in solidarity we need to take ownership of the issue and assume responsibility
of the role of agents of change. We can take a lot of encouragement from Agnes Houston’s perspective on this issue. She says “whoever you are, but especially if you are a health professional working with people with dementia, you can be part of the battle to confront stigma. If you, like me, have dementia do not be ashamed, don’t hide, join with me to confront stigma.”

**NEXT SLIDE**

**SLIDE XX: ASI**

I now ask your permission to spend a few minutes introducing the Alzheimer Society of Ireland and sharing with you some of the actions we have taken in Ireland to challenge the meanings of dementia and the ways in which we are attempting to reframe the messages about what dementia really means.

We are, like many of the Alzheimer organisations throughout the world, are both a service provider and an advocacy organisation. We were founded by carers 30 years ago but we are very much a hybrid type organisation with carers and people with dementia jointly owning the organisation. However, like others, we still have a distance to travel, to ensure the equal place of the person with dementia in our organisational structures and activities.

**NEXT SLIDE**

**SLIDE: FROM DUBLIN TO PERTH ?**

You may also be wondering why someone from Ireland travelling 15,000 kilometers ended up addressing you today? Well, Alzheimer organisations are networked internationally and part of the philosophy of this networking is to share and learn and often challenge ourselves too. There is a tremendous sense of solidarity among Alzheimer organisations in that we share so much in terms of the road we are all travelling on together. So this journey is in fact about building relationships, working in solidarity and
supporting each other to be meaningful and effective in what we do together but also build our capacity as individual organisations. It is about developing what the Australian Alzheimer association has dubbed ‘intellectual capital’. In fact, we in Ireland have drawly hugely on the Alzheimer Australia’s experiences and expertise in particular in their work of making dementia a national health priority. As you will see in a few minutes we hogged more than just one their ideas in the past. Australian health and social models are often quoted as the best models in the world and when we do our research we often find ourselves in Australian cyber space. As recently as last week I heard a conference speaker in Ireland extol the virtues of your palliative care services having had first-hand experience of her son die in a Sydney hospital. So be proud and respectful of what you have and the high regard you enjoy on the world stage. So it’s really about more about me listening and doing lots of learning over the next few days. However, my husband and two children at home remain to be convinced that this is the only reason for my travelling to this amazing country and not just the realisation of a long held dream to swim in the Indian Ocean and see real kangaroos!!!

NEXT SLIDE

SLIDE 15: TAKING ACTION IRISH STYLE

Standing outside the national parliament building here is a group of people with dementia and carers who participated in our first ever National Consumer Summit and who lobbied senior national politicians as part of the summit. We continue aim to place dementia at the heart of politics and the democratic process and the main way in which we do this is support people to have their voices here in the milieu of the policy making process.
SLIDE 17: DEMENTIA MANIFESTO

This national summit led to the development of a Dementia Manifesto a sustained 3 year national campaign to make dementia a national health priority. There is now a commitment from the Irish Government to commence the development of a national dementia strategy. We are key partners in this process. In the meantime, we continue to politicise dementia and have it viewed as a political and economic issue that warrants significantly greater levels of attention. We have secured philanthropic funding to support us in this work. Both the summit and the manifesto were ideas we stole from the Australian association. In fact any of you who are familiar with the first Australian dementia manifesto will see striking similar to the one we produced!

SLIDE X: NATIONAL ELECTION 2011

In keeping with the political theme for the moment we had a national election in our country two months ago. The Alzheimer Society was very active at the grassroots and the national level in terms of getting our message out and we designed a range of printed material, including this voter prompt postcard that provided information and prompted questions for the election candidates. What was unique about this election campaign was that we literally brought dementia to the high street; setting up information stands in the shopping centres and public spaces we invited the election candidates to join us as well as seeking public support for our campaign. It was amazing to experience firsthand encounters with people with the condition, carers, family members, former carers and not too surprisingly a few uneducated members of the public. What was interesting is that there was enough courage in the organisation, among people with dementia and their families to go ‘public’ and face down the stigma. This
was a very encouraging experience for us an organisation and we celebrated when we saw the commitment in black and white in the new programme for government to develop a national dementia strategy by 2013. In terms of tackling the stigma, there clearly is roll for very public events that grab media attention which this did.

NEXT SLIDE

SLIDE XX: DEMENTIA FRIENDLY COMMUNITIES

I already mentioned the multi-faceted way in which we need to tackle the stigma of dementia and a new and exciting initiative that is emerging on the landscape is a concept called ‘Dementia Friendly Communities’. You probably all have heard about age friendly communities so this concept is an extension of that. Essentially, the initiative is about transforming our villages, towns, cities and communities into better places to live for people with dementia: it is about facilitating local communities to enable people living with dementia to live in their own community and retain their traditional networks. It is about mainstreaming dementia in our communities. It is not about setting up ‘new’ services, but instead supporting the existing community to become dementia friendly and inclusive. Some countries in Europe have begun the process of rolling out the concept and the work and we have have started the pre-development working towards the roll out in September of a Dementia Friendly Communities project in one of our towns pictured here in the mid-west.

The model places the person with dementia at the centre and gives them a meaningful voice in determining the place they wish to occupy in their community.

Dementia awareness training and education is the key to having dementia friendly communities. People living and working in the community need to understand dementia in order to be able to respond appropriately.
addition to the awareness building, the need for low level ‘one-to-one’ support by a volunteer or ‘buddy’ was universally identified as the crucial link for the person with dementia. to engage/re-engage in their communities. In practice, this means that there a person who understands dementia would become a ‘buddy’/companion in order to accompany the person with dementia on a trip to the shop, pub, library, taking a walk or, going to the gym/park.

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**SLIDE 18: EILEEN AND RUTH O’REILLY**

They say a picture tells a thousand words. Isn’t it so true? This is an award winning photo that appeared in the paper of note in Ireland. You are looking at Eileen O’Reilly, who was diagnosed with dementia at 54 with her daughter Ruth, sharing a treasured moment. Isn’t there so much beauty and love showing in this stolen moment? Do you see any stigma here?

**NEXT SLIDE**

**SLIDE 19: MICHAEL NOONAN**

This is a well known national politician Michael Noonan who was recently appointed the Minister for Finance. While in office as minister for health in the 1990s his wife, Florie was diagnosed with Alzheimer’s disease. However, he told nobody until he went on national television recently, almost two decades later, to tell his story in the hope that he would encourage others carers to ‘come out’ tell their story and not to ‘hide’ behind dementia. And in fact, his story gave permission to many people with dementia and their carers to ‘come out’. I have met many of these people in recent times. He was the catalyst for a whole lot of public debate and gave people the confidence to talk opening about dementia. He has also agreed to become the leader of the Cross Party Friends of Dementia group in the parliament.
On the left of this photo is Joe English who is a 53 year old man diagnosed with dementia chatting to a national broadcaster who is supporting our work. Joe featured in a programme called Forgotten Lives that was broadcast in May on national television highlighting the issues that he and other people living with dementia face. His honesty and openness are immeasurable. We need more and more people like Joe to share their story. The broadcaster, on the right, Pat Kenny, has used his position as a broadcaster to create awareness and dispel some of the myths. So we are gradually cultivating a community of willing dementia champions. Are you part of that community? What do you say about dementia in public and private conversations?

I mentioned that I wasn’t going to talk about facts and figures earlier but that does not take away from the need for a strong evidence base for the work that we do. A number of years back, we commissioned research in the Alzheimer Society of Ireland on the perceptions of stigma in dementia. This ground breaking report, in an Irish context, provided us with the evidence and gave us a platform as an organisation to confidently start new conversations and question the current status quo. We really believe that research is central to building all of our intellectual capital. There’s that word again!
So let’s once and for all slay this particular dragon. No swords or knights are needed! It can be done through talking, listening, learning, leading and changing for good the world that we all live in. **Let’s set the stage, rewrite the lines, carve out new roles for the whole cast of actors that need to be involved.** Together we can lead the way to create a future where people with dementia are active citizens and dementia is just another part of our everyday lives. **Let us be the change we want in the world.**

To finish, I quote the words of author Terry Pratchett who says

“**talk openly about dementia because ... if we are to kill the demon then first we have to say its name**”

Here are my contact details. My sincere thank you to you for listening.