



**Proceedings of the
Younger Onset Dementia
Summit**

23-24 February 2009

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Acknowledgements

Summit participants wish to thank:

The Convenors of Parliamentary Friends of Dementia, Ms Sharon Grierson MP and Senator Marise Payne and Alzheimer's Australia for jointly hosting the Summit.

The Minister for Ageing, The Hon Justine Elliot, MP and the Shadow Minister for Ageing, The Hon Peter Dutton, MP, the Shadow Minister for Health and Ageing and Mrs Margaret May, Shadow Minister for Ageing for taking part in the Summit.

The Governor-General, Her Excellency Ms Quentin Bryce, AC and His Excellency Mr Michael Bryce, AM, AE for their hospitality.

The Australian Government for providing the funding for the Summit and making it possible for participants to come to Canberra.



YOUNGER ONSET DEMENTIA SUMMIT PROGRAM 23rd and 24th February 2009

22nd February	
5.00 pm -6.00 pm	Reception for participants at Government House
23rd February	
8.15am	Participants picked up from Rydges Capital Hill
8.30am	Coffee/tea at Rydges Lakeside
8.50am	Introductions and housekeeping
9.00am	Minister welcomed by Associate Professor Marc Budge, President, Alzheimer's Australia Sharon Grierson MP, Convenor Parliamentary Friends of Dementia Welcome by The Hon. Justine Elliot, Minister for Ageing Liz Forsythe to introduce speakers Presentation by consumers (Minister has to leave at 9.30am for Parliament)
10.30am	Allocated rest break and coffee/tea
11.15am	Working Groups <ul style="list-style-type: none"> • <i>Working Group 1- Awareness and Stigma</i> • <i>Working Group 2 - Delays in Diagnosis</i> • <i>Working Group 3 - Access to appropriate services</i> • <i>Working Group 4 - Employment and financial issues</i> • <i>Working Group 5 - Impact on quality of life</i> • <i>Working Group 6 - Legal and Bureaucratic Issues</i> Each group will have: <ul style="list-style-type: none"> • A consumer as chairperson supported by an AA staff member and an advisor with a sound knowledge of the topic. • Chairperson will act as the group's spokesperson reporting back at the Plenary Session. (Consumer to be supported if necessary by a staff member)

<p>1.00pm</p> <p>2.30pm</p> <p>3.45pm</p> <p>4.00pm</p> <p>4.30pm</p> <p>4.40pm</p> <p>6.30pm</p>	<p>The tasks of the Working Groups are to:</p> <ul style="list-style-type: none"> • Discuss the issues set out in the pre-Summit consumer consultations briefing (relevant to the particular Working Group). • Consider and revise the relevant section of the draft Communiqué. • Report back to the full Summit. • AA staff to write up feedback in a suitable form for conference proceedings document. <p>Lunch + allocated rest break</p> <ul style="list-style-type: none"> • Plenary Session: Report from Working Groups by a consumer from each group, followed by questions from the floor/comment by experts. The objective is to discuss what will be reported to the Minister and Shadow Minister and included in the draft Communiqué. • Feedback from Partnership group <p>Allocated rest break</p> <p>Professor John Hodges research presentation</p> <p>Communiqué drafting group appointed</p> <p>Close</p> <p>Dinner at Rydges Capital Hill</p>
<p>24th February</p> <p>8.15am</p> <p>8.30am</p> <p>9.00am</p> <p>10.30am</p> <p>11.00am</p> <p>12.00pm</p> <p>12.45pm</p>	<p>Participants picked up from Rydges Capital Hill</p> <p>Coffee/tea at Rydges Lakeside</p> <p>Discuss and finalise the draft Communiqué</p> <p>Coffee/tea</p> <p>Next Steps</p> <p>All participants taken to the Mural Hall, Parliament House</p> <p>Presentation of the Communiqué by a Summit participant to the Minister for Ageing, The Hon Justine Elliot, the Shadow Minister for Health, The Hon Peter Dutton and the Shadow Minister, Mrs Margaret May and Parliamentary Friends of Dementia at Mural Hall, Parliament House. Light lunch will be provided</p>

Glenn Rees, CEO, Alzheimer's Australia at Government House

Thank you, Your Excellency, on behalf of Alzheimer's Australia and Summit participants for your welcome and this reception.

It was a great help to us in organising the Summit to have your early agreement to give this reception and to meet Summit participants.

As I think you would understand Governor General, the advocacy journey can be a long one and at times lonely and frustrating. This is especially so on social issues such as younger onset dementia, which is so little understood in the community.

It is important to remain positive even though the journey might take years before those in a position to do so make a commitment for action. But like water dripping on a stone the time will come when the goal is achieved.

Along the way though there will be times during the journey like this Summit to value and remember. This Summit is such an opportunity. It enables people to come together who have the passion, commitment and determination to convey the message to the wider community and those at the political level. By the end of the Summit we hope to have agreement on issues and the action required.

At the end of the journey we can look forward to the moment when the message finally seeps through the political system and the person with the power to take decisions asks "What do you want?" and means it.

The Summit will, I am sure, provide many great moments. And this reception has been a wonderful way to start. It is progress that the Summit is being held and funded by the Australian Government.

I am sure we would all wish you well in continuing the wonderful start you have made as Governor General in raising issues of concern to the Australian people.

So let me thank you Governor General on behalf of all of us for this reception and for being Patron of Alzheimer's Australia.

Many thanks

OPENING OF YOUNGER ONSET DEMENTIA SUMMIT

President, Alzheimer's Australia, Associate Professor Marc Budge

Minister, Members of Parliament Sharon Grierson and Annette Ellis. Most importantly welcome to all the Summit participants who have travelled from far and wide to be in Canberra. Thank you.

Thank you, Minister, for being here to open the Younger Onset Dementia Summit. I know how busy you are and how difficult it is to get away from Parliament during a sitting week.

I can confidently say it is the first Summit of this kind and that even a few years ago such an event would not have been contemplated or funded.

We thank you Minister, for making this Summit possible through the funding provided by the Australian Government. The funding has also supported two new publications "In our own words..." and "Younger Onset Dementia: A Practical Guide". These are important new resources to promote awareness of younger onset dementia through the moving stories of younger people with dementia and to provide practical information to younger people with dementia and their families and carers.

I should acknowledge too an unconditional grant from Novartis to develop the Guide. The organisation of the Summit owes a great deal to the two convenors of Parliamentary Friends of Dementia - Sharon Grierson and Senator Marise Payne – and their staff.

Indeed, we have received tremendous support from Parliamentary Friends over recent years and from Annette Ellis and other Parliamentarians who have attended meetings and supported Dementia Awareness Week. And we look forward Annette to the report of the Committee you are Chairing in the House of Representatives on Better Support for Carers.

I know Minister that you have a strong commitment to ensuring that consumer advice is part of the advice you receive. The strong representation of consumers on your Dementia Advisory Group is testament to that.

We are looking forward to the publication of the evaluation of the Dementia Initiative - Making Dementia a National Health Priority later this year in May, and to working with you and your Department in helping to frame the decisions the Government will be taking on the Dementia Initiative in the 2010 budget.

The outcome of the Summit will make an important contribution to the priorities that are determined for the next 5 years of the Dementia Initiative. I know the Summit participants are looking forward to handing over to you tomorrow the communiqué containing the priorities for action as they see

them. Thank you again Minister for your support. It is now my pleasure to hand over to Sharon Grierson.

**SPEECH FOR THE HON JUSTINE ELLIOT
MINISTER FOR AGEING
OPENING: ALZHEIMER'S AUSTRALIA YOUNGER ONSET
DEMENTIA SUMMIT
CANBERRA
23 FEBRUARY 2009**

Acknowledgements

Alzheimer's Australia,

Mr Glenn Rees, National Executive Director and

Professor Marc Budge, President and Summit Chair

Fellow members of Parliament

- Thank you for inviting me to open the Younger Onset Dementia Summit this morning.

- I would like to welcome and acknowledge those of you with younger onset dementia, and those who provide support – families and carers.

- Also I would like to thank those of you from peak organisations supporting people with younger onset dementia.

- Thank you for your commitment to this important issue and for your participation in this valuable summit.

- The Prime Minister Kevin Rudd also recognises and acknowledges the work being conducted by all of you and in particular Alzheimer's Australia and it gives me great pleasure to read you a message on his behalf.

**MESSAGE: ALZHEIMER'S AUSTRALIA YOUNGER ONSET
DEMENTIA SUMMIT, 23-24 FEBRUARY 2009**

Dementia affects the lives of nearly one million Australians, including those who care for an affected family member or friend.

It can be a terrible disease affecting not only a person's health, but also their relationships with loved ones and even their sense of personal identity.

What many Australians don't realise is that around five per cent of those with this challenging condition are under the age of 65 years, and some are as young as 35 years.

Thank you to the many Australians with caring responsibilities, for their dedication and commitment in supporting people with dementia during some of the most difficult times in their lives.

The Australian Government is committed to supporting dementia awareness, research and care, and provides more than \$120 million per year under the Dementia Initiative.

This includes annual funding of: \$90 million for Extended Aged Care at Home Dementia Packages; \$24 million for dementia research, prevention, early intervention and improved care initiatives; and \$7 million for training for aged and community care staff, carers and community workers.

Alzheimer's Australia is to be congratulated for their good work in raising awareness of dementia and supporting those affected, and in particular, for drawing attention to the plight of younger people living with early onset dementia.

I trust this summit will provide delegates with an opportunity to share their skills and experiences and I wish the very best to participants.

The Honourable Kevin Rudd MP
Prime Minister of Australia

Introduction

- For the broader community dementia is difficult to fathom.
- We often associate dementia with older people – it is something that you ‘get’ when you’re in a nursing home.
- But for many of us here today, we know that sadly this is not the case.
- It is estimated that about 10,000 Australians have younger onset dementia.
- As I am sure many of you are aware it is a condition that affects people in the prime of their life – in their 50s and 40s, and sometimes even their 30s.
- The first sign may be when they struggle doing something basic which they have been doing for years such as cooking a meal or going to work.
- A person with younger onset dementia often faces additional challenges to those faced by older people due to the stage of life they are in.
- This group comprises people with expertise in dementia, a person living with dementia and a carer.
- The group has met four times and has already provided valuable feedback on a range of issues including the evaluation of the Dementia Initiative and targeting areas for the recent round of Community Grants.

- I am sure that this summit and its outcomes will also be a valuable addition to the dialogue and policy discussions that are underway.
- The Australian Government's National Respite for Carers Program supports carers by providing respite, information and carer support services.
- More than 600 community-based respite services are funded under this program to deliver services in a variety of settings – including carers' homes, day centres and overnight cottages.
- About 475,000 Australians are primary carers¹. Over the years, this program has helped so many of them by giving them a break from their usual care arrangements – which helps people stay in their community. Last year alone, 118,000 carers² received respite assistance through the program.
- Many of the services are specifically funded to provide respite for the carers of frail older people and people with dementia.
- I have visited some of these services and heard first hand how they assist families and carers. This is by allowing the carer to go to work for a few hours or whether it is to go to the shops.
- That is why I am pleased today to announce that funding of more than \$12 million over the next two and a half years will be allocated to 35 respite service providers under the National Respite for Carers Program.
- This will enable them to offer new or expanded respite services to meet local needs.

- Through the Australian Government's Dementia Initiative funding was also made available to develop a training resource – launched last year – designed to increase the knowledge, understanding and expertise of carers, aged care workers and community workers in caring for people with younger onset dementia.
- We recognise that the education of health professionals can have tangible impacts for everyday life.

Conclusion

- While there is a lot of work underway – the need to address the future direction of care and support of people with younger onset dementia in Australia is a big task.
- So we'll move forward – with Alzheimer's Australia and drawing on the knowledge and priorities identified through this summit – to continue raising awareness of younger onset dementia.
- To keep building vital support networks so that people living with the condition can stay connected to their friends, families and communities.

¹ Report on the Operation of the Aged Care Act 1997, 1 July 2007 to 30 June 2008, p.30

² *ibid* p.31

Summit Participant Speeches

Patricia Fogarty

HOPE – Helping Other Possibilities to Emerge

Let me introduce our thirty eight year old son Ged.

2007 was witness to Ged's transition from one of Melbourne's "*hottest jewellers*" with a very successful business located in Collins Street to a life of dependency upon others, due to the early onset of the crippling and debilitating Dementia.

After being a magnificent provider, wonderful husband and exceptional father to two little children, aged one and four years, Ged is now confined to live with us his parents as a place of last resort.

The cognitive impairment and brain dysfunction caused by the disease prevent him from participating in the majority of his past loves, either work or pleasure. The illness requires him to be monitored and supervised constantly.

Early in 2007, when Ged was 36 top specialists in the neurological field were sought to explore some solutions. Although we were spared the harrowing ordeal of waiting for a diagnostic outcome, the shock, grief, disbelief and anger that prevailed within the family following the medical report's outcome was profound.

When members of the medical profession identified and proclaimed their diagnosis of frontotemporal dementia, the capacity to sustain a meaningful life for Ged began to dissolve. This solution was shaped and framed upon three themes:

- ❖ This was a seriously hopeless situation.
- ❖ All Ged's autonomy (physical and financial) must be removed.
- ❖ A Nursing home placement should be sought.

Initially Ged spent his time living at home with his wife and children, with Richard my husband & I providing welcomed respite.

Large mortgage repayments required some negotiations to enable time for the magnificent home they had built only eighteen months prior to be sold. With the grief of 'losing' the man she had married, their family dreams and life aspirations shattered, together with the challenging task of providing comfort and guidance to the children, Ged's wife Megan was perplexed and bewildered.

It soon became evident that the intermittent respite options needed to be frequent. By May 2007 Ged began to spend 70% of his time with us in the NSW country town of Deniliquin. The remainder was spent in Melbourne with his young family.

His condition however, placed enhanced stressors upon Megan and the children. Following 'professional advice' Ged was placed in an Aged Care Nursing Home in July, some fourteen weeks after diagnosis.

At 36 years of age this was an enormously challenging time for Ged and his extended family. With the youngest resident at the facility being 74 years of

age, Richard and I together with the support of our eldest son defied the 'professional advice' believing this step was both premature and inappropriate given Ged's capacities, abilities and age, the lack of age appropriate facilities offered, and the limitations in trained staff catering to the needs of a younger resident.

Following exigent and difficult discussions with Ged's wife who held the belief she had acted upon expert advice, Ged quickly left the facility.

Our greatest challenge at this point was the 'professional advice' that had determined Ged's institutional placement had been based on the "*usual pattern of people living with dementia*". I asked the question – How many 36 year olds were included in the evidence base and what consideration had been given to individual and family strengths and capacities in making the determination? The outcome was obvious – nil!

After much family heartache it was decided that Ged would live with us and return to his home in Melbourne for brief routine visits every three to four weeks. This required Richard to give up work and become a full-time carer, and myself to move to part-time work in order to allow respite for Richard.

The heartache caused by competing needs and conflicting 'professional advice' throughout this timeframe has driven a wedge through what was once a strong and united extended family relationship. Over the past twelve months Ged has had minimal contact with his wife and daughters.

A new model of service delivery that complements the medical model of care, with a mix of social and relational approaches needs to emerge. Flexible and creative responses need to be sought to dismiss the hopelessness and deliver a fresh approach.

Based upon three themes I believe the fresh approach needs to embrace:

- ❖ HOPE - Helping Other Possibilities to Emerge.
- ❖ Implementing a focus upon individual and family strengths that compliment those capacities with creative responses.
- ❖ Developing individually tailored 'wrap around services' which will assist in reducing family and individual stress.

I am convinced, investing in services to reduce family stress in relation to the care of those whose lives have been so profoundly impacted from younger onset dementia, will not only deliver benefits to those battling the illness, but also to the entire community, both in terms of social inclusion and financial cost savings.

Throughout the past eighteen months with the assistance of friends, Ged's brother and creative respite carers, complemented by contemporary medical thinking, a regime has been established to enable Ged to remain connected to friends and community happenings. Friends have rallied to support Ged in numerous ways including financial. We endeavour to keep everybody connected by encouraging visits and production of bi-monthly newsletter. The rapid onslaught of the disease has plateaued. But for how long we can sustain this we are not sure!

Therefore, we must explore flexible and responsive residential respite and longer care options that take into account the unique needs of younger people living with dementia. This would mean placing the client at the centre of the focus, offering a range of 'shared' care options - not one size fits all, which to

date, has been our experience. I would hate to think the number of times I have heard the words, “*conditioning to institutional care*” proclaimed. In turn I would ask - what about conditioning the environment to meet the needs of the person?

What has happened to the guiding principles of United Nations Conventions on People with Disabilities? “*Full and effective participation and inclusion in society; respect for difference and acceptance of persons as part of human diversity and humanity*”.

We must look to developing age appropriate services that foster engagement and focus upon promoting strengths and the wellbeing of the person experiencing younger onset dementia and his/her carer or carers.

We must enrich research developments to ensure that the future burden of this disease is minimized or diminished with the dawning of a new era of hope.

In delivering HOPE – let’s determine that the primary goal of this Summit is to provide better care and support to younger people with dementia and their families, thereby ensuring their quality of life and level of wellbeing is optimized. So that young people like Ged whose lives are so drastically altered by the onset of degenerating illnesses, are offered a little of life’s “*carrot*” and be cared for in a loving and appropriate environment that has been engineered to cater for their specific needs.

David Anderson

Increased awareness to reduce stigma and social isolation.

It seems that when you have Cancer you are a brave battler, but when you have Dementia you are an old “fart”.

In my former life I was a Business Manager and Accountant in the State Public Service and was employed for 36 years.

I barely remember the context of the words when attending my first medical consultation which had been arranged by my employer to address work performance issues.

Quote: “I am confident that you are extremely depressed and I am suggesting treatment in accordance with that opinion. Your symptoms are similar to those of dementia, however at 52 years old that is an extremely remote possibility and we should rule that out”

I breathed a sigh of relief at hearing that qualified opinion and set off armed to the hilt with antidepressant medication which I dutifully consumed in ever increasing dosages, and for the next 14 months living in hope that I would be able to return to work. Over this period the improvement in the symptoms, difficulties and ability to cope was exactly zero.

I was then sent for a neuro - psychological assessment which resulted in a finding of decreased brain function, memory loss and other related cognitive difficulties not expected in a person of my age and professional training. I was referred to a specialist and was diagnosed with younger onset dementia which would be progressively assessed as time passed.

When my employer was informed of a diagnosis of dementia it was inferred that I should consider accessing my superannuation early and resign so that my position could be filled. Communication and support for me had diminished over my period of absence and with this diagnosis any empathy was gone.

I was employed by a Government organisation whose charter was primary health care and yet knowledge, awareness and information relating to dementia was non existent although access to information on work related injuries, diabetes and drug abuse and HIV was readily available.

Invitations to social events with work colleagues and friends for my wife and I reduced to virtually nil as most people preferred not to handle the prospects of meeting me and dealing with whatever social interaction with us could now bring.

It was like having a dreaded contagious disease.

I said to one person who was extremely anxious when interacting with me
“you can’t catch it , you know”

With the onset of any dementia based disease we develop feelings of lack of self worth, lack of confidence, reduction of ability to cope with daily issues,

feelings of uselessness, being a burden on the family, confused, and disorientated in a common environment, so the stigma of dementia becomes a crushing blow to deal with.

A person living with dementia needs to be regarded as a socially acceptable, useful and valued person in society. With this in place they can regain a footing with life and contribute too many aspects of the community.

The lack of information and awareness in the broader community generates the ill informed opinion that a person living with dementia has a greatly reduced ability to contribute to society. This opinion fuels the growth of the stigma of dementia and the person is excluded from social activities especially as the disease progresses. It is accepted that the person living with dementia may not be able to function in the role that they once played, however, with education and support it is evident that new ones can develop.

In my opinion education or awareness programs are the key to challenging the stigma of dementia, however I feel these need to be on two fronts;.

Firstly, accurate, consistent and current information is required for the person living with dementia, their carers, families and friends. We require support and assistance with issues such as understanding the journey that we are about to undertake, counselling to assist in the process of acceptance of the disease and encouragement to challenge the stereotype view. This "training" would help to regain a measure of self esteem and worth, which encourages the building of confidence. In challenging this stereotype we display to the world that we are useful and capable in our own right to continue a productive and enjoyable life. Therefore, we feel empowered and the load is reduced on the carer and support services.

Secondly, National Awareness and Education Programs need to be created to educate the public about the many kinds of dementia. It is important that these programs are easy to follow and are geared to educate, and not threatening people.

They should be made with intense contribution from people living with dementia and the facts explained from the world that they now live in. Unlike "The Grim Reaper", and "Quit" programs which tend to use fear/scare tactics to transmit their message, dementia programs should be concentrating on the support and understanding aspects which would assist people to overcome the burden of this stigma. There needs to be a serious recognition of the statistical facts that dementia related disease is going to be a far bigger medical problem in the 21st Century than most people think or wish to admit to. The future cost of not acting now will be enormous in both human and financial terms.

Any Australian Government social inclusion policy and initiative must include younger people living with dementia. With the early onset of dementia, access to support mechanisms is imperative due to the impact on people who are at a stage of their lives where they would normally be working, supporting a family, paying a mortgage, contributing to the gross national product of Australia and paying income tax. Excluding them will continue to increase the burden on medical and social security services.

Issues confronting people living with dementia, their carers and families with relation to social security services in particular need addressing within the education programs.

It is evident that the stigma of dementia remains confronting and at times threatening when dealing within government organisations due to the fact that it is a “hidden” disease.

Dementia knows no boundaries and multi cultural and indigenous people would experience an added intensity to these problems, and public education and awareness is the only avenue for all of us.
We are one, we are Australians.

My favourite caption from a poster that I saw not long after being diagnosed is;
“Life doesn’t stop when Dementia starts”

Believe it...it’s true.

A quote from a person living with dementia in the United Kingdom:
“I don’t want sympathy, I just want understanding.”

Thank you all for listening.

Paul Wenn

Delays in Diagnosis

My partner Tony Walsh and I have been together for 20 years.

I was diagnosed with Alzheimer's in October 2006 at the age of 63. I was also diagnosed with Parkinson's a year later.

What I want to talk to you about today is the long path we had to take to reach the Alzheimer's diagnosis.

I was taking a new drug for a lung infection 1996 and had been warned that this may cause memory loss and deafness. Partial deafness had already been diagnosed and when I began to experience memory loss I raised it with my GP in 2003. He referred me to the local memory clinic attached to a large hospital. They forgot to make an appointment and this was the first big mistake.

The issue here is that at an early age I identified a problem – asked for help and it was not forthcoming. This underlines the need for good administration when dealing with people with bad memories.

After a few months I raised it again with my GP and the first appointment was made with the memory clinic in 2004. The clinic asked in their letter fixing the appointment that I should be accompanied by a friend or family member – the most useful advice ever given. Tony has accompanied me to all the consultations and taken notes. You need help to find your way round the system and sometimes we have used our notes to fill gaps in the official record.

It was decided at the first appointment that my symptoms needed further investigation. Tony must have been visibly shaken because a nurse who had sat in on the consultation took him for a cup of tea and a chat whilst I went to do the first of many tests. Unfortunately this was the last time for some time that anyone talked to him alone about what was going on.

A long process followed during which I was tested for the physical problems that could be causing the memory loss. All proved to be negative. We were told repeatedly that the problem was one associated with mood and not brain damage. I was diagnosed with mild depression causing memory loss. The first attempt at treatment was using St Johns Wort and then Ginseng and some sessions with a psychologist.

At the end of each session Tony would spend time trying to calm me down. Unfortunately he was not given the chance to raise this at later consultations. This brings me to a very important issue. When someone is being treated for a suspected memory limiting

disease, when and how should a close third party be involved? Our experiences tell us that if they are not involved this leads to difficulties and prevents an important source of information being tapped.

After further tests at the original memory clinic and because there was no improvement, I was referred to a psychiatrist and took more anti-depressants. The psychological tests had continued to show that the problem was one associated with mood and not brain damage.

A reoccurring theme which we recorded was that most of the practitioners involved thought that I could not have dementia because I was too young. At that time, we saw this as a reassurance rather than a criticism.

Luckily our GP grew very irritated with the lack of a substantive diagnosis. He decided to act and he asked for my authority to explore the records held by other people. In July 2006 he was copied a PET scan report dated April 2004 which concluded that and I quote “the FDG PET scan of the brain is suggestive of early Alzheimer’s.” He copied it to the psychiatrist I was seeing and a diagnosis of Alzheimer’s came very quickly and I started on Aricept.

This was a real shock and we decided to put the matter from our minds and be pleased that we had a diagnosis at last. Whether or not we did the correct thing is open to question. We wonder if we had at least advised the original memory clinic that they appear to have missed or mislaid the original diagnosis we may have made it easier for those coming behind us.

As soon as the diagnosis had been made we contacted Alzheimer’s Australia and within a short time we attended a course for people who had been diagnosed at an early age. This was very valuable and it was great to meet other people who were facing the same issues. We were interested to hear at the first session that two other couples mentioned that they were very relieved to have reached a diagnosis and they like us went out that night to celebrate – I think that is a measure of the pressure of not knowing.

The early onset group also helped us in one other important way. Talking to others it became clear that I initially may have been on the on the wrong dose of Aricept. We were able to raise this with the medical practitioners, the dose was changed and we began to see the drug take effect.

In 2007 Tony noticed that I was developing an arm tremor and we brought this to the attention of our GP who made contact with another clinic. They rapidly diagnosed the problem Parkinson’s and have insisted on maintaining contact and periodic reviews.

To sum up – we believe that early diagnosis is important, patients and partners should be encouraged to keep records and most important carers and partners should be consulted and included well before diagnosis. All these we think will lead to the process running smoother.

Patricia Henwood Quality of Life

I was 37 years old, a single mum, living in Perth with my two children who have autism and the rest of my family (siblings) residing in Queensland. I was a registered nurse, but had taken time out to be with my children. Life was great, life was 'normal'. Then my family was contacted by an estranged uncle who advised that my aunty had been diagnosed with a very rare form of younger onset Alzheimer's due to genetic mutation and had died at the age of 52. Our father passed away when we were all very young, so obviously we had no idea that this existed in the family. Luckily my siblings and I are close and we had frank discussions about the illness. Individually we all decided to 'get tested' to see if we carried the gene - if we did carry it, it was definite that we would develop the disease. Of the four siblings, 3 of us were diagnosed with it. I am the oldest at 40 and therefore the 'Lab Rat'. By that I mean that they will learn from my experiences.

There are a number of concerns that cross your mind at different times, these include the effects that my diagnosis will have/ has had on my children. There is a lack of counselling services with any expertise in this area for children. It's not uncommon to have younger onset dementia and teenage children. My two children are now 15 and 17 but were only 12 and 14 when I was diagnosed. I worry about the emotional effects that this has on them. It must also be going through their minds from time to time that they may have the disease, which is a lot for anyone to deal with. There is a need for appropriate expert counselling for my children and this needs to be ongoing. Medication was also a big worry for me. I am willing to try anything to see if it can slow down the process, but the current regulations prescribe the appropriate medication (anti-cholinesterase) only when you reach a certain score on the mini mental tests. A neurologist actually told me that you have to be in severe stages before you are eligible for the medication. This was inaccurate and I am eligible to be prescribed this drug on PBS, but this information was not available to me until recently when I saw a private psychiatrist, which I had to pay for myself.

Because of my nursing background I am in a very different situation to others because I know what signs to look for and I know that it is going to happen, but when I seek help I am told to go away and come back in a year, because I can't possibly have younger onset Alzheimer's at my age. I have to take records and information along with me everywhere I go, otherwise I am not believed. Even private psychiatrists have this approach. I find that unless I sit there and explain my knowledge, they don't want to know about it and dismiss it. I was fortunate to be referred to the James Cook University Psychology Unit by AANQLD and I undergo testing every 12 months to compare with previous results. This reinforces to me that I am not 'making it up' or 'sending myself loony' and it also assists me in providing documented evidence to the medical profession.

I believe that I am fortunate to have a nursing background. This has assisted me in meeting with doctors, understanding medical terms and knowing what to expect (which at times could be a double edged sword). However I wonder how other people get on who do not have this background.

There are no facilities for me when I am unable to care for myself. There are whispers here and there about an age appropriate facility in Brisbane but I want to stay in Townsville. One huge concern to me is that I will be placed in an aged care facility with people twice my age that I cannot relate to and I will be isolated. I don't expect facilities to be available in every town and I would move to Brisbane for this, but some information or confirmation would be nice.

There is a huge information gap about the particular genetic form of Alzheimer's that I have. I understand that it is very rare and that this information is not yet known, again I may be the Lab Rat that paves the way, but it is very unsettling not knowing. Doctors also don't know or understand it, It is a very difficult position that probably can't be fixed in the near future. The only reference that we have is my previously estranged uncle, whom we stay in contact with and he provides us with information as to my auntie's signs and progression. The only information that anyone can give me that has substance is that she died at 52 years of age, not something for me to look forward to really.

I worry that people will take advantage of me because of my degenerating state. I have always been fiercely independent and I struggle with the fact that not everyone is honest and that some people won't assist you if they think they can get away with it, including government departments. I have 2 autistic children and my 17 year old daughter can be very violent. I have cared for her until recently but she is now in foster care because I am unable to control her violence and my son and I are no longer safe. I went to the Department of Child Safety and Disability Services to get assistance and to advise them that she can no longer live with us. I was told that they cannot find placements for her and that they would apply for a Guardianship Order (which means that they have complete control and decision making ability and my right as a parent is forfeited). Luckily my sister worked in the child protection field and was able to help me. We then had to argue and fight and eventually the department dropped the guardianship application. At times I felt this was a deliberate tactic by them to persuade me into keeping my daughter in my fulltime care. I believe that this disease makes it very difficult for me to fight for my rights and the rights of my children.

Of all these concerns, I know that there are some that may never be answered or 'fixed' and some that may be sorted too late for me, and also some that only relate to me and my situation, but I hope I have given you a little understanding of what goes on in the world of a person diagnosed with Alzheimer's at 37.

Samantha Sinclair

A small amount of knowledge

Genetic testing and the advent of personal genomics are incredible technologies, but they also raise some complex ethical questions. The ability to see our genetic makeup has the potential to impact on our lives in ways that we have yet to fully comprehend. If you were offered the chance to read your own genetic story, would you want to? And if a genetic test revealed that you would develop a disease that had no cure, how would you cope with that information? Would it empower you to make the most of your life or would it overwhelm you with grief and fear?

Would knowing that you would develop a fatal degenerative illness such as Alzheimer's disease change the way you lived your life, and perhaps make you consider how and when you might want to die?

Several years ago I had genetic testing to determine if I had inherited a specific mutation that had been found in my mother's DNA. This mutation had been identified as the cause of familial younger onset Alzheimer's disease, which claimed her life 3 years ago in March, at 63 years of age.

This type of Alzheimer's is rare, affecting approximately 1-5% of those diagnosed with dementia. In each family it is caused by a mutation in a single gene, and a copy of that gene, inherited from one parent, will cause the disease. Each child has a 50% chance of inheriting the mutation from an affected parent.

My mother had it, and therefore I had a 50% chance of also having it. The age of onset is usually between 35 and 55 and as with other forms of dementia, there is currently no cure. I have since discovered that this disease not only cut short my mother's life, but also the lives of loved ones in her family for more than six generations.

Genetic testing is available to those who are considered at risk of inheriting this disease when a specific genetic mutation has been identified and a family history of dementia is evident. It can be used to confirm the presence of a familial Alzheimer's gene in a person who already has symptoms. But it can also predict who will develop the disease in the future.

I chose to undertake testing for several reasons.

Firstly, my mother had been misdiagnosed with depression for nearly ten years before being told that she had younger onset Alzheimer's. By the time we knew what was happening, it was too late to make real changes to the quality of her life. Watching the light in her eyes slowly fade as the disease took hold was heartbreaking - and I would not wish this experience on my worst enemy, let alone on those I love.

I realized that genetic testing offered me the chance to gain knowledge that had been denied to my mother and my family, and that this knowledge could enable me to prepare and plan for what might lie ahead. My mother's misdiagnosis meant that many precious years were wasted and I did not want

that to happen again if it was in my power to do things differently.

I was also hoping to have children of my own. I knew that if I had inherited the disease, then any child of mine would have a 50% chance of having familial Alzheimer's disease. I could not responsibly consider having children without knowing whether I might be risking their lives by passing on the mutation. I also felt that my partner at the time had a right to know what the future might hold for him if I was found to have the mutation.

Some people can live with uncertainty, and some can't. I like to know where things are at. My father would tell you this is because I am a control freak and he is probably right, but I felt that I could live with the results of the test, better than I could live with constant doubt. A small amount of knowledge can be a dangerous thing and for me, the stakes were already too high for ignorance to be bliss.

Anyone who has experienced the grief associated with losing someone they love to dementia, knows it is not only those who carry the disease that suffer.

I chose to have genetic testing because I felt that if I did in fact, have the mutation, this would affect the choices and lives of others, as well as my own.

The decision to proceed with genetic testing is an entirely personal one, and it is not my intention in any way to influence others who might consider this option for themselves.

I will say this though. If a person chooses to be tested, they can never go back. The information they receive will be with them for the rest of their lives. And for this reason, it is essential that testing should only be undertaken after participating in genetic counselling to ensure that the decision is made in a timely manner and from an educated and well-informed position. It is important too, that this counselling is of a quality to meet these needs.

Receiving the results of a genetic test that shows a person has inherited younger onset Alzheimer's disease when they are a perfectly healthy 30 year old would most likely be very different to receiving the same results at 50, when signs of the disease may have already begun. In saying this, I am in no way meaning to diminish the impact that a positive genetic test result or diagnosis of dementia can have at any age. I merely wish to illustrate that the issues will not be the same for every individual.

Studies have indicated that in some cases, those who already had signs of Alzheimer's actually found relief in a positive genetic test result because it provided an answer to what was happening to them, and allowed them to plan for the future. Those with a negative test will find instant relief in their own results but may experience guilt if a sibling turns out to be affected.

For those younger, asymptomatic people who carry the mutation, some try to make their own silver lining by using a combination of in vitro fertilization and pre-implantation genetic diagnosis to have an unaffected baby. Others go ahead with a natural pregnancy, but may choose to terminate if prenatal testing shows that the mutation has been passed to the foetus. And there are some who risk everything and take their pregnancy to full term, hoping that a

cure will be found in their child's lifetime.

Some will participate in research themselves in the hope that a treatment may be found in time for them.

To be at the forefront of new science can be a lonely and bewildering experience. How we as individuals cope with knowing our genetic destiny, and how we as a society balance the benefits versus the potential harm of such knowledge, remains to be seen.

Every day, more and more diseases are identified as having a genetic basis. I think that the challenge to live with our genetic identities will be as much social as it is scientific.

If we are going to continue to offer genetic testing for hereditary diseases such as familial Alzheimer's, Huntington's disease, Parkinson's disease and other hereditary forms of dementia, then we need to not only provide best practice care, services and facilities to those affected by these illnesses, but also commit our national will to finding a cure for these diseases. This commitment needs to happen now and not later, because later is just too late.

Leo White
Dealing with the Bureaucracy
The Good, The Bad and the Ugly

I was an organisational development consultant and most recently, I was working as an Executive Coach, meeting with individuals over several periods, sometimes five or six times, sometimes twenty times. I was required to remember either through my notes or my memory, every part of every conversation so I could draw upon them when needed. I had an almost photographic memory, so I very seldom referred to my notes.

I had taken a trip to the US and had been gone for a while, and on coming back had a last minute assignment. I went to it and discovered that I had met some of these people before. Not only did I not remember the details of the conversations, I didn't remember them and I was horrified, shocked. I came back and I really started to think about it more and became depressed and so I saw my doctor for depression. I went to him and said, "I'm depressed". I had had several bouts of depression throughout my life and I've always responded well to medication. So I started medication. I did not get better. I got worse.

When he realised that I wasn't getting better, he didn't do what many would do (which would be to increase the dosage). He said, now lets wean you off of this and try something else if it's not working. Shortly thereafter I became confused while driving in downtown Launceston. I knew that I was in downtown Launceston, I knew which street my car was parked on, but I did not know how to get to the place I was trying to find and I did not know how to get back to my car. Eventually, with help, I found my car and I sat there in my car and things slowly reconnected and I figured out how to drive home. Along the way home, I said to myself "That's the kind of thing that happens to people with Alzheimer's, but that can't be the case, because I'm too young". So I saw my doctor (I made an immediate appointment) and that came to this...

The Good

Once I told him of that event, he immediately scheduled me with three referrals. A CT scan, which proved to be largely negative. A referral to a Neuro psychologist and also a referral to another medical doctor who I later found out is a geriatric researcher.

So the good part was the psychological testing, which began almost immediately, revealed over a two month period that "I had a dementia, possibly Alzheimer's". Further testing by the psychologist, who is also a counselling psychologist whom I continue to see, verified that diagnosis. This was later also verified by a geriatric psychiatrist. So that all went well.

The Bad

It took almost four months to get an appointment with a referral to the medical research doctor. He does not have a private practice and is only assessable through a specialist clinic at the Launceston General Hospital. He was the only person in the Launceston area who could prescribe Aricept™. It's worse than that, because after three months, I had not even been given a date for my appointment. I went to the hospital and basically told them I was not leaving until I had an appointment. They bounced me around, but I said, "No, I'm not leaving". I got an appointment, however that didn't help much because the appointment was hurried and basically he did not listen to me. He asked me questions and I would ask him questions and he would go "No, no, don't worry". Basically, he physically examined me, determined that I knew something about what was going on in general and scheduled me for further blood tests.

Now everything I have said so far are facts. This is an opinion.

(Slide)

"It is my OPINION that he (Medical Research doctor) wasn't interested because my condition didn't match his current area of research (which is hydrocephalus pressure dementia) and hurried me out of his office so that he could get back to his research!"

I am not going to say his name, but it was the most hurried, uncaring, non-listening thing I have ever experienced. He gave me my sheet to get my blood tested and left me to find it. Of course, I got lost and had to get help. He then scheduled me for another appointment in three months (after my blood test to come back). They all came back negative.

The Ugly

This was going on at the same time as waiting for the appointment with the medical researcher. I had applied (because of my doctor and my neuro-psychologist diagnosis) for a disability pension. I was given a job capacity assessment with a psychologist. In the assessment interview, he was quite supportive and understanding and he told me, among other things, "you have a dementia, and you're not fit for work". We talked about Aricept™ and other things.

A month later I received a decision, denying my claim. Basically they did not assess me on my dementia, because it wasn't fully stabilised. One of the reports that I had given them stated that I wasn't stabilised, I would get worse. Also, the psychologist at Centrelink had taken the fact that I wasn't on Aricept™ to say, "Oh, when you begin the medicine you might get better, and you can probably be rehabilitated". I was devastated and went back to my neuropsychologist and she went to work for me.

Closing

She (the neuropsychologist) put me in touch with Advocacy Tasmania and with the Launceston Legal Clinic. One of the good things about speaking with an American accent is that if you tell someone you are going to sue them, they believe you! The person at Advocacy Tasmania, Ms Hillary Brown, was wonderful. She got me an immediate appointment with a geriatric psychiatrist in Hobart who confirmed my diagnosis and started me on Aricept™ that day.

My lawyer filed an appeal and worked together with Advocacy Tasmania and my neuropsychologist. A month later I got a letter to say they had reversed their decision. No more medical reports were needed, just letters from my doctors saying I would not stabilise I would only get worse and could not be rehabilitated.

That process was overwhelming. I was so despondent because both the refusal by Centrelink and the doctor who basically dismissed me occurred within a week of each other, and I was ready to give up. But because my wife, Ellie, and my neuropsychologist, Dr Emma McCrum and my primary physician, Dr Michael Aizen, pushed me on and helped me get through it.

Thank you.

Richard Stubbs Employment Issues Made to Retire!

I'm convinced that long before most people admit to it, they have already known for quite some time before that, that they had a memory loss of sorts, and it must have already affected their day-to day performances, long before the final truth was out. We're not silly. I remember disguising my problem from my close friends and workmates, long before I was finally found out.

When it started happening to me, I wrongly consoled myself by saying 'well, I'm now in my early sixties, surely forgetfulness is just another part of growing old. Of course I was totally wrong.

As most people reach sixty years of age, they know or have already planned what they want to do in their retirement, but I enjoyed working and I also enjoyed my job and I intended to work until I was at least seventy years of age, and sadly it was only a few months after making that decision, that I was told I was unfit to work any longer, simply because I couldn't remember certain things.

An instant appointment was made for me to see the Commonwealth Medical Officer and that very same week I found myself out of a job. The CMO, in his wisdom, had declared that I was Totally and Permanently Incapacitated and unfit to carry out my normal duties in the maintenance of government buildings.

In a way I couldn't blame the government for being worried that in a case of a fire, a gas explosion or a major incident, un-intentionally I may forget or get confused in the heat of the moment, thereby putting twenty something staff members and three hundred and fifty students lives at risk and who could argue with that!

This was all happening some eight months before my sixty-fifth birthday, and being silly I was half expecting or at least hoped, that they might have given me 'light duties' and allowed to retire with a little dignity. It's not very flattering when you are 'made' to retire.

Naturally, I appealed against the decision, politely requesting a second opinion. I have to lower my head when I tell you, that the second report was even worse than the one I'd received from the government CMO, simply because we now live in an age of litigation and they can no longer take any chances with a forgetful employee, whether he or she is a good worker or not.

It hurt me real bad at the time, being told that I would never work again, and as individuals, we all handle this sort of news differently, I'm ashamed to say that I didn't handle it at all well. I found myself being plummeted into a deep state of depression and I was wallowing around in self pity, being full of remorse and disappointment. It was not a pretty sight I can tell you.

But thinking back, why shouldn't a conscientious hard working guy like myself feel despondent? I'd worked two jobs from the moment my little legs first

stepped onto Australian soil nearly forty years ago, and now being told to go home and get hooked on doing crossword puzzles and the like, sent me deeper and deeper into depression. I ceased any involvement with my many life long hobbies and it wasn't long after, that I'd hit rock bottom.

At around this same time, my dear friend and ex business partner Graham, phoned me and asked would I like to call into the Trophy centre and meet all the old staff again. I suspect my lovely wife may have had a hand in this somehow. Graham felt sure I would be interested in seeing how things had progressed with the advent of modern computers, instead of the old - fashioned hand engraving methods.

I had a smile on hearing the same old problems we experienced years before and I was able to help with suggestions and methods we used in the old days. Ever since that visit I've been a regular caller every Wednesday to the centre.

For some crazy reason, which I cannot explain, it made me feel good having to shave and get dressed tidily, I was able to kid myself that I was going back off to work again. My payment each week was several thick slices of white bread, spread with 'real' butter, filled with lashings of healthy cheese and sliced leg ham. All of these delicacies are strictly 'off limits' in my own home.

At the same time, a very rare 1939 Malvern Star 98cc auto-cycle, which was rusting away in pieces ended up on my work bench. Suddenly my inner gyro started spinning once more and I felt the urge to pull on a pair of overalls again.

At the same time, I felt the need to start drawing and painting again. Sadly my neighbours were 'horrified' when they heard me tickling the ivories on my old piano once more?

In the beginning, I withdrew into my shell like a frightened snail, but now I'm able to accept my problem and I'm now living again. As a life member of Apex I've re-commenced looking after two 'very' senior citizens, and I find there's something nice about being socially engaged, and valued!

Mihaela Safta

The Experience of a Working Carer

As I stand here to give a speech, it is a good thing Mum is not here as she might leave me speechless. It's not often that I am left speechless, but Mum manages to do it occasionally. Like the time she walked in on me in the bathroom and I said: "Excuse me, do you mind?" To which she replied, "I don't mind at all".

My journey as a carer for Mum started in December 2006 when I decided to take over her care. She was 64 at that time and had just been diagnosed with Alzheimer's Disease. That day I had no idea what lay ahead for us. It was just as well, as I might have decided it would be all too much.

For the first 10 months, Mum lived with me at home. Two weeks after she moved in with me, I received a phone call from the police while I was at work. They had Mum in custody having arrested her for inappropriate behaviour.

That day was the beginning of a period of 9 months of absolute frenzy. Mum was arrested 4 times. There were 5 court appearances. We had 34 appointments with various medical specialists and other health professionals. And that day was the beginning of the realisation of just how ill Mum was.

In the end, the diagnosis was changed to Frontal Temporal Dementia and the high risk behaviour placed her at the top of the priority list. She received a place in a psychiatric ward where she could wait for a place in residential care. A psychiatric ward is not a place to care for someone with dementia, but at least now she was safe and well looked after. The police dropped the charges against her only when she was admitted to the ward. She stayed there for 10 months until a place became available at the high-dependency unit in Perth, the only one of its kind, the only one who could cope with her behaviour. It takes only 8 residents at a time.

Having Mum in residential care does not make things any easier. The management strategy at the care facility makes a difficult situation totally unbearable at times, as the strategy is designed to make things easier for the staff only and nobody takes into consideration the impact it has on me. They don't have to comply with the WA Carers Act. Hardly any organisation does.

Making the choice to care for Mum as my number one priority was easy. Managing the impact that choice had on my professional life was tough. I estimate I worked maybe 6 months during 2007. During this time, my workload remained at full time load. It was the boom time. Even when I was physically present at work, I was mentally absent. Did I remember to turn the gas off at the meter as I left home? Was I going to get another call from the police that day? All my energy was going into dealing with the medical and the law professionals and pushing for a resolution. On a good day, my productivity was maybe 20%.

It is difficult to estimate, but my guess is that it cost the company I was working for somewhere between \$100 and \$300,000 dollars in additional

project costs. For a project manager used to controlling project costs and the project schedule, that was very challenging for me to deal with.

Two years on, the impact on my professional life has lessened somewhat. The impact on my personal life is just as great.

There are some funny moments, although sometimes I see the funny side much later. Mostly there is grief, guilt, exhaustion and the burden of making tough decisions across all areas of my life. They are my constant companions these days.

Grief is what I feel as I watch her deteriorate and turn into a different person. Grief is what I feel as I realise how much potential she had and never realised, because she never believed in herself and accepted less than she deserved. Grief is what I feel when I think of the relationship we never had and never will.

Then there is the time involved, the time I had to take away from other activities I used to enjoy but had to give up.

These days I know and I accept that it is impossible for me to meet all of my commitments, all of the time. Each day I have to make a deliberate choice about which aspect of my life will get the highest priority: No matter what choice I make, there is guilt associated with it.

Then there is the exhaustion – physical and mostly emotional. Managing my exhaustion levels is vital as I cannot cope with Mum's behaviour when I am too tired.

Something else I have to manage is the realisation that Mum had behavioural symptoms for about 10 years prior to diagnosis and like most people, I associated only forgetfulness and not personality or behavioural changes with dementia and attributed her increasingly difficult behaviour to other reasons. She realised there was something wrong and tried to tell me about it many years ago and I ignored her. While that shortened the period I had to deal with the dementia, she had to struggle on her own, with no support, in those early stages. Now she is no longer aware of the severity of her condition, which is a blessing. I don't think I could cope with her grief as well as mine.

Mum's siblings disapproved of me telling even the family of mum's illness. In Romania, disability of any sort is shameful and therefore hidden. They would certainly not approve of me speaking out here.

Being a carer for someone with dementia is a very difficult journey, but it can be incredibly rewarding. In illness mum has given me a gift that she was unable to give me in health – emotional maturity, finding my inner strength, confirming my values and my priorities in life. I have learned patience, understanding, acceptance and tolerance. I still had to do all the work myself, but it was worth it. And most important of all, I have made my peace with her.

And when it all gets too much I think of what the Dalai Lama said: "once you know things are always changing, even if you are passing through a very

difficult period, you can find comfort in knowing that the situation will not remain that way forever”.

RESEARCH PRIORITIES IN YOUNGER ONSET DEMENTIA

Professor John Hodges, Federation Fellow – FRONTIER, Prince of Wales Medical Research Institute, Barker Street, Randwick NSW 2031
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1. The fundamental aim: “The cause and cure of younger onset dementia”
2. Factors to consider
 - Wide range of causes of YOD
 - Many are rare ‘orphan diseases’ of low priority to funding agencies and big pharmaceutical companies
 - High proportion of genetic causes compared to late onset dementia
 - Many people with YOD and their families are unaware of how they can contribute to research, particularly importance of brain pathology
 - Size of problem in Australia is unknown.
3. Short to Medium term goals
 - Epidemiological study of YOD to establish prevalence and causes in Australia
 - Greater attention to impact and burden on caregivers
 - Comprehensive study of genetic factors and prevalence of gene mutations
 - Improve early diagnosis of differentiation of dementia subtypes : eg. brain imaging, biomarkers etc.
 - Funding of treatment interventions : pharmacological, cognitive and behavioural
 - Increase enrolment into brain banks



YOUNGER ONSET DEMENTIA *Not too young for dementia*

23-24 Feb 2009
Canberra

COMMUNIQUÉ

“It’s all about HOPE – Helping Other Possibilities to Emerge”

Summit participants

Dementia strikes at any age. It profoundly affects the quality of life for thousands of younger Australians everyday.

This communiqué and supporting recommendations address how the quality of life can be maintained and improved for people with younger onset dementia, their families and carers.

The Summit

More than 100 people attended the Summit. The Summit involved primarily people with younger onset dementia, carers from all States and Territories and also key partners¹ working with people with younger onset dementia.

Alzheimer’s Australia calls on the Australian Government to recognize the needs of people living with younger onset dementia by providing dedicated funding for services that meets their unique needs.

Younger onset dementia

Younger onset dementia is the term used to describe any form of dementia with onset of symptoms in people under the age of 65. It is estimated that younger onset dementia affects approximately 10,000 people in Australia today.

The needs of this group are special because there is low awareness, even among health professionals, that younger people may have dementia. Due to this there is poor access to services that provide care and social support for younger people and their carers and the condition can have a devastating impact on the person with younger onset dementia, their family, their children

¹ Alzheimer’s Australia invited AIDS Dementia and HIV Psychiatry Service, Alcohol Related Brain Injury Australian Services (ARBIAS), Down Syndrome NSW, Huntington’s Disease Australia, National Stroke Foundation, Motor Neurone Disease Australia, Multiple Sclerosis Australia – ACT/NSW/Vic, Parkinson’s Australia and Young People in Nursing Homes National Alliance to the Summit.

and their friends. People have a right to tailored dementia services regardless of age.

Priority Areas

Participants at the Summit identified six priority areas that require action:

1. Increased awareness to reduce stigma and social isolation.
2. Timely and accurate diagnosis.
3. Access to appropriate services.
4. Employment and financial needs.
5. Legal and bureaucratic issues.
6. Increased investment in research.

A partnership approach

Complementing these priorities, the partners endorsed the building of closer collaborative links between Alzheimer's Australia and groups concerned with Down Syndrome, Motor Neurone disease, HIV/AIDS, Parkinson's disease, Huntington's disease, Multiple Sclerosis, alcohol and drug abuse, and stroke that may result in younger onset dementia.

These organisations have agreed to work together in developing common organisational positions on the priorities agreed by consumers.

ACTION POINT 1

INCREASED AWARENESS TO REDUCE STIGMA AND SOCIAL ISOLATION

“You’re too young for dementia”

A local General Practitioner

Background

‘You’re too young for dementia’ is often the reaction of doctors, health professionals, family and friends of people with dementia because society associates dementia with ‘old age’.

Awareness is the key to reducing the stigma of younger onset dementia.

Issues

- **Younger onset dementia does not discriminate** across culture, gender, socio-economic or any other context.
- **Lack of information, awareness and understanding** in the broader community, and amongst professionals and service providers, increases the stress for younger people with dementia. Friends and family struggle when others don’t recognise or underestimate the difficulties that people with younger onset dementia and their family and carers experience.
- **Culturally, linguistically and religiously diverse communities** struggle to increase awareness and reduce stigma because the word ‘dementia’ is often overlaid with shame or the person being seen as “mad or crazy”. Often the concept of dementia does not translate into a culturally understandable concept which further exacerbates the stigma associated with younger onset dementia.
- **Younger people with alcohol-related dementia** receive less empathy and often attract more judgemental attitudes in the public view.
- There is limited awareness that the **person with younger onset dementia has the right to be involved in their own care.**

Recommendations

1. A national awareness and social marketing program focusing specifically on younger onset dementia be developed, involving younger people with dementia telling their stories. This program should be funded by the Australian Government and developed and delivered by Alzheimer's Australia.
2. Aboriginal and Torres Strait Islander communities and culturally, linguistically and religiously diverse communities be included in awareness raising programs that are respectful of their diversity.
3. Younger people with dementia be recognised and supported in the Australian Government's social inclusion policies and initiatives including:
 - a. More inclusive workplace practices.
 - b. A greater emphasis on supporting people living with younger onset dementia in their families and in their communities.

ACTION POINT 2

TIMELY AND ACCURATE ASSESSMENT AND DIAGNOSIS

“Finding the correct diagnosis was extremely difficult and put the whole family under extreme stress for a number of years before the correct diagnosis was given”

Carer

Background

It can take many years to get an accurate diagnosis. Lack of awareness among many medical professionals means symptoms are often attributed to other life stage events such as menopause or work/relationship stress or depression. People with younger onset dementia are more likely to have rarer forms of dementia which may necessitate the involvement of many different specialists.

Issues

- **Delay in diagnosis** delays both treatment options and future planning.
- There is **limited access to specialist diagnostic services for younger people** with cognitive and behavioural changes.
- In metropolitan areas General Practitioners are the most common first point of contact. In a regional and remote area it may not be the General Practitioner but other allied health professionals. The **lack of awareness and education** of younger onset dementia by General Practitioners and allied health professionals can lead to delays in diagnosis.
- **Rural, remote and isolated areas are more disadvantaged** by the lack of specialist support available within their communities. Transport costs for travelling to medical appointments are significant and often unaffordable.
- The **wide range of diseases** (such as Multiple Sclerosis, alcohol related impairment, HIV/AIDS, Parkinson’s disease, Motor Neurone disease and Stroke) that can result in younger onset dementia makes the diagnosis and management particularly challenging.
- There is a general **lack of awareness regarding the availability of genetic testing and no national framework for genetic testing** for younger onset dementia. Access to testing and the cost of testing is variable and expensive. Most genetic tests are not listed on the Medical Benefits Scheme.
- **Criteria for access under the Pharmaceutical Benefits Scheme for dementia medications** are restrictive, particularly for younger people with dementia.

Recommendations

1. A nationwide network of accessible specialist diagnostic clinics to assist people experiencing memory loss or cognitive changes be developed.
2. All health and community service professionals encompassing neurologists, nurse practitioners and allied health professionals participate in dementia awareness initiatives.
3. Dementia Training Study Centres, in consultation with the Division of General Practitioners, develop continuing education programs targeting General Practitioners, nurse practitioners and allied health professionals in dementia related issues.
4. A national framework for genetic testing be developed and implemented and supported by adequately resourced and skilled counsellors.
5. A range of appropriate and current clinical diagnostic tools be developed to streamline the assessment on younger onset dementia. Financial incentives and education strategies are needed to encourage the uptake of such tools into practice.
6. Review guidelines for accessing pharmaceuticals and diagnostic procedures for people with younger onset dementia to ensure they have access.

ACTION POINT 3

PROVIDE ACCESS TO APPROPRIATE SERVICES

“We just don’t fit anywhere”

A person with younger onset dementia

Background

Dementia can occur at any stage of life – rarely in the teens and the 20’s and increasingly in the 30s and beyond. A dedicated younger onset service will have greater capacity to identify more relevant options for younger people with dementia and their families.

Issues

- Services need to be **age, culturally² and gender appropriate**. They need to be available to all people including those living in regional, rural, remote and isolated communities.
- People who are **consumers want to have a say** in what happens to them.
- **Support must be innovative, flexible and responsive** to the needs of carers, partners and children of those with younger onset dementia. Models of care, embracing consumer directed care and empowering carers and younger people with dementia should be trialled and implemented, particularly in respect to respite care.
- Younger people with dementia living alone may need to consider **‘technical aids’** in their home to help maintain function, safety and independence. These may include assistive technology that promotes orientation, security, medication compliance, safe use of home appliances and communication options.
- For those families and carers who combine work and family responsibilities, **respite care is critical** and needs to:
 - ~ be meaningful for the person with dementia;
 - ~ be available in a form that matches the needs of the person with dementia and their family;
 - ~ be consistently facilitated by a trained support worker who should have the flexibility to provide a service to different people across different settings including regional and rural areas;
 - ~ operate outside standard business hours and include weekends.

² Including new and emerging communities.

- **Long-term out-of-home care** is a matter of great concern to many younger people with dementia and their families. There is a need for alternative options to be developed outside of residential aged care facilities that include the capacity to move in and out of long-term care needs change.
- **Care workers need training.** Staff caring for younger people with dementia and their families require a different skill mix to meet the unique needs of younger people with dementia.
- **Children of younger people with dementia are often disenfranchised** of their childhood or adolescence. They may be vulnerable and at risk of many indicators of ill-being since often both parents are absorbed in the business of simply coping and adapting. Children need to be supported throughout their parent's dementia journey.
- **The health of the carer is often neglected** because of numerous other demands which may include young children, older parents, work commitments. Carers often lose contact with friends and family due the social isolation often experienced by people with dementia.
- Access to **appropriate counselling** is an essential component in assisting the person with younger onset dementia, their partner, carer, children, and parents to ensure their well-being.
- **Relationship breakdown**, before or after diagnosis, contributes significantly to a lack of well-being for the whole family. Individuals, couples and families need support to maintain their relationship and respite is an important enabler in this process. The latter may be seen as an activity which can sometimes facilitate 'whole family' outings in which a support worker facilitates positive dynamics.
- Issues of **intimacy and sexuality** are often neglected. Health professionals need to keep open an invitation to enter the discussion.

Recommendations

1. The Australian Government, State and Territory Governments review accommodation services for people with younger onset dementia to ensure that the needs, values and expectations of younger people with dementia are identified and met.
2. A targeted strategy be implemented to improve the range and quality of in home and out of home services available for people with younger onset dementia, their carers and families including those living in rural, regional and remote areas.
3. Relationship re-engagement programs be developed as part of a suite of counselling options available for people with younger onset dementia.

4. A range of transport alternatives be readily available to allow people access to community services.
5. Programs be established to support carers to ensure that their health and well-being needs are effectively met.
6. Guidance should be provided to care staff on issues related to intimacy and sexuality to assist them in responding to the needs of people with younger onset dementia.
7. Following diagnosis, a key worker within health services be appointed (who is identified in consultation with the person diagnosed and their carer) as a single point of contact. The key worker role will be to support the achievement of short and long-term goals identified by the person with younger onset dementia and their family.
8. Younger people with dementia and their carers be empowered through models of consumer directed care to make decisions about the community and residential services they require.
9. A younger onset dementia funding stream be established to provide innovative approaches for age appropriate respite and long term residential care in partnership with people with younger onset dementia, their family, their carers and service providers.
10. A training strategy for health professionals and all direct care staff underpin a focus on quality care in responding to the unique needs of younger people with dementia.
11. Each Alzheimer's Australia State and Territory Office is funded for a worker to promote partnerships with culturally, linguistically and religiously diverse organisations and Aboriginal and Torres Strait Islander organisations on issues related to younger onset dementia.
12. An online directory of resources be established, funded and maintained for younger people with dementia and their families. The aim of this resource is to streamline access to appropriate up to date information.
13. Services be established to meet the social, emotional and psychological needs of children of people with younger onset dementia.
14. People with younger onset dementia remain eligible for services that are established prior to the age of 65 to ensure continuity of care.

ACTION POINT 4

EMPLOYMENT AND FINANCIAL NEEDS

*“Work called me and told me he was being sent home.
It appears things had been going wrong for some time.”*

A spouse of a person with younger onset dementia

Background

Demotion, early retirement or selling the family business (in rural communities this may be family property) are frequent outcomes of cognitive decline either before or after diagnosis. The consequence is likely to result in significant financial stress for the person and their family.

Issues

- Unemployment results in:
 - ~ Financial loss at a time of significant financial demands.
 - ~ Increase in ‘alone’ hours often leading to lowered self-esteem and depression.
 - ~ Increase in social isolation.
 - ~ Partners either being forced back into the workforce to meet the financial gap or being required to cease work because of their partner’s increasing care needs.
 - ~ High impact on family lifestyle.

- Financial Issues:
 - ~ Person may resign prior to diagnosis without accessing their full entitlements.
 - ~ Consumers are often unaware of their entitlements in accessing superannuation.
 - ~ Cash flow problems.
 - ~ Loss of business and capacity to maintain self-employment.
 - ~ Increased medical costs.
 - ~ Some couples have to declare that they are legally separated to fund long term placement for the person with dementia.
 - ~ Carer payment and carer allowance are often denied in the first instance.

Recommendations

1. The Australian Government establish an advisory board of younger people with dementia, families, carers and service providers to formulate new approaches:
 - ~ Remove the inequities that younger people with dementia and their family carers face accessing and maintaining their employment, in terms of superannuation and/or income security entitlements.
 - ~ Review all relevant legislation to ensure that the rights of people with younger onset dementia are recognised and protected.
 - ~ Review and streamline assessment processes, tools and forms to establish a person's illness, injury or disability and ensure that claims processes are simplified.
2. A program be developed and funded to support younger people with dementia in maintaining a sense of purpose and achievement through participation in full time or part time work, volunteer or recreational activities.
3. A 'Dementia Awareness in the Workplace' program be developed and made available to support employers and employees in the workplace. This program should focus on people with younger onset dementia and carers.
4. Employers be encouraged to retain people with younger onset dementia in employment should they wish to continue to work. As part of this initiative employment alternatives should be considered where available (e.g. the Supported Wages Scheme) and where appropriate, to ensure that employees have a range of choices before the termination of their employment is considered.
5. The Australian Government review the terminology for those who are "totally and permanently incapacitated" so as to reduce the stigma associated with disability.

ACTION POINT 5

LEGAL AND BUREAUCRATIC

“Kids tormented him and we had parents take him to court and tried to have an AVO taken out against him and have him locked away because the kids were in the park... and the mother was adamant that he was going to attack them”

Family member of a person with younger onset dementia

Background

Legal and bureaucratic systems, which are complex and at times inflexible, place additional burdens on people with younger onset dementia and their families.

Issues

- Access to dementia-specific legal expertise is needed after diagnosis to assist with future planning regarding **powers of attorney, wills and advance care directives**.
- Some people with **younger onset dementia may find themselves in conflict with a legal system** which has little understanding of dementia. A person with dementia may commit theft, exhibit violence and/or commit sexual misdemeanours as a result of their condition.
- Some organisations **do not recognise an Enduring Power of Attorney**.
- Some travel insurance policies have a **‘dementia exclusion clause’**.
- **Issues with private health insurance** may be problematic for people with younger onset dementia.
- Younger people’s sense of identity is threatened when they are required to **relinquish their driver’s licences**. This situation is made more difficult by the fact that there are often few viable transport alternatives.

Recommendations

1. The Australian Government works with States and Territories to achieve greater harmonisation in legislative provisions and terminology for power of attorney and advance care directives.
2. The Australian Government ensures that the Commonwealth Disability Discrimination Act more effectively applies to people living with younger onset dementia and their carers.
3. The Australian Government establish an independent Dementia Advocate to provide legal assistance and advice to people with younger onset dementia and their carers.
4. The Australian Government works with insurance providers to ensure standard terms and conditions that recognise the rights of people with younger onset dementia in the provision of all types of insurance.
5. The Australian Government work with States and Territories to achieve more appropriate and equitable arrangements for those with younger onset dementia to support them to maintain their driver's licence in light of their individual capacities.

ACTION POINT 6

RESEARCH

“It is in research we will find the cure – we need to balance investment in responding to current needs while continuing to seek the cure to younger onset dementia”

Health professional

Background

Quality research promotes improvement in practice which improves the quality of life of people living with younger onset dementia.

Issues

- There is **inadequate information** on the number of Australians who have younger onset dementia and its causes.
- There is a need for more research into disorders that affect predominantly younger people such as frontotemporal lobar degeneration and the **rarer genetic forms of dementia**. Most cases of Alzheimer’s disease resulting from genetic mutations occur in younger people.
- There is **inadequate information about the effectiveness of different models** of care.
- **Dementia is not one of the priority areas of the National Health and Medical Research Council.**

Recommendations

1. There needs to be greater investment into research into the cause, cure and care of younger onset dementias. This should include inherited diseases and other conditions causing dementia.
2. Research is needed to identify more accurately the numbers of those with younger onset dementia and models of care that are responsive to the needs of people with younger onset dementia and related conditions.
3. People with dementia have the opportunity to be involved in dementia research, including setting priorities and disseminating results.
4. There needs to be an initiative to encourage enrolment into brain donor programs since fundamental research into the dementias is heavily dependent upon these resources.

5. There needs to be greater awareness amongst consumers (people with younger onset dementia and their families) of centres of excellence for research particularly those participating in clinical trials.
6. Dementia should be included as a National Health Priority Area by the National Health and Medical Research Council.

**Joan Jackman, David Anderson, Paul Wenn, Tony Walsh and
Patricia Henwood
Presentation of Communiqué at Parliament House**

Minister, Shadow Ministers, Members and Senators, ladies and gentlemen,

We have had an extraordinary day and a half of robust discussion and debate, between ordinary people living extraordinary lives with younger onset dementia. The result is this communiqué we present to you today.

It identifies that dementia can strike at any age. It affects the life of thousands of young Australians and their families every day.

Our recommendations show how the quality of life can be maintained and improved for people with younger onset dementia, their families and their carers.

So we thank you Minister for funding this valuable opportunity to meet with others from around Australia and thank you also to the Parliamentary Friends of Dementia for doing what they always do – help to raise dementia to a political level.

Thank you.



Peter Dutton MP
Federal Member for Dickson

Younger Onset Dementia Summit – comments for Alzheimer’s Australia

Dementia is a truly cruel illness not just for those that suffer from its terrible consequences, but for those family and friends who surround them and who face the difficult, indeed daunting challenges of caring for the sufferer.

In most people’s mindset it is an affliction that affects those in older age, too many remain unaware that it can and does affect people much earlier in their lifetimes.

It makes your summit to highlight the impact of Younger Onset Dementia extremely important to those younger Australians who are dealing with this devastating condition.

Official estimates are that around 1700 Australians under 65 are affected by early onset of dementia, but I note that Alzheimer’s Australia considers the numbers to be much higher, around 10,000.

For them and those that will be afflicted in the future, the work that you doing now is vital to providing better outcomes.

Four years ago the Howard Government acted to counter the serious impacts of dementia, making it a National Health Priority and I’m proud that it provided significant funding for research and work on prevention and care.

I commend the Rudd Government for pressing ahead in this vital area.

It is one of those issues where we must all work together, providing a strong bi-partisan approach to make progress against an ailment that already affects several hundred thousand Australians.

Many people come through the doors of this national Parliament with stories that touch our hearts, yours are among them, and I’m glad that you have been able to bring this matter to us as parliamentarians and representatives of the Australian people.

We will take the report from your summit and consider its recommendations and I hope that we can live up to your expectations.

Attendees of presentation of the Communiqué at Parliament House

The Communiqué was presented by consumers to the Minister for Ageing, The Hon Justine Elliot, MP, Shadow Minister for Health and Ageing, The Hon Peter Dutton, MP and Shadow Minister for Ageing, Mrs Margaret May MP. There were a number of members of Parliamentary Friends of Dementia present including

Jodie Campbell MP – Member for Bass, Tasmania
Yvette D’Ath MP – Member for Petrie, Queensland
Senator Mark Furner MP – Senator for Queensland
Gary Gray AO MP, Member for Brand, Western Australia, Parliamentary Secretary for Regional Development and Northern Australia
Sharon Grierson MP – Member for Newcastle, New South Wales
Senator Bill Heffernan – Senator for New South Wales
Sussan Ley, MP – Member for Farrer, New South Wales
Kirsten Livermore, MP – Member for Capricornia, Queensland
Senator Marise Payne, Senator for New South Wales
Brett Raguse, MP – Member for Forde, Queensland
Senator Dana Wortley – Senator for SA

Next Steps

Glenn Rees, CEO, Alzheimer's Australia

This Summit is not an end in itself. You have the right to expect that the issues and action identified are pursued.

The opportunities to build on in respect of younger onset dementia over the next 12 months are:

- The outcome of the Council of Australian Government in June/July on responsibilities for ageing and disabilities.
- Government and Parliamentary reviews – Health and Hospitals Commission, Primary Care Review, Health prevention task force, Parliamentary Inquiry on Better Support for Carers
- The 2010 budget when the Dementia Initiative – Making Dementia a National Health Priority is to be decided for the next five years. The Government and the Opposition have committed to continue the Initiative with existing funding. The challenge, of course, is that additional funding will be needed for new initiatives, since the larger part of the funding provided in the 2005 budget is locked in to ongoing recurrent funding for high care packages and other programs.

Immediate possibilities that come to mind in terms of following up the Summit are to:

- Write to the Prime Minister with the Communiqué suggesting that in the context of COAG's discussions, younger onset dementia should be a National issue if awareness and reform in access to programs is to be achieved.
- Request the Minister for Ageing to consider the scope to fund services for younger people with dementia through existing programs.
- Draw the attention of the Minister for Health and Ageing to the issues that younger people experience in obtaining a diagnosis.
- Continue to pursue the inclusion of younger people with dementia in the social inclusion policy of the Federal Government.
- Continue to promote awareness of the issues of younger onset dementia through the activities of AA including through wide distribution of "In their own Words..." and Younger Onset Dementia: A Practical Guide.
- Seek opportunities to work with service providers in promoting proposals for innovative care in respect of services for younger onset dementia people.
- Build on discussions with partner organisations in the Summit in key areas including advocacy for greater awareness of younger onset dementia, access to services and advance care planning.
- Ask participants from the Summit to approach Senators and Members in their States with the draft Communiqué with a view to enlisting their support in securing national action on younger onset dementia, especially in respect of access to new services.

- Arrange for a group of consumers meet with Centrelink to pursue changes in the documentation required and any other issues.
- Future discussions with Parliamentary Friends of Dementia
- Consumers to lobby their local members with copies of communiqué
- Means for consumers to network - State Consumer groups? Chat network on web? Regular teleconference of a national group?
- National register of GPs and specialists who are YOD literate
- Circulate a regular newsletter on younger onset dementia that includes the action being taken on the Communiqué and news about news services