FIGHT

FIGHT DEMENTIA CAMPAIGN UPDATE

FIGHT ALZHEIMER'S
SAVE AUSTRALIA
FIGHTDEMENTIA.ORG.AU
Dear Champions,

This week I had the opportunity to give a presentation for the National Press Club in Canberra on the theme of “Towards a World Without Dementia”. The main focus of my talk was my concern about the stigma that continues to attach to dementia and the lack of understanding in the community about dementia as a chronic disease. For a copy of the speech, click here.

I reported on the Fight Dementia Campaign, what we have achieved so far and how we have used your stories to raise awareness about the needs of people with dementia. I also focused on the work that remains to be done.

I raised my concerns about the way our community responds to individuals with a diagnosis of dementia. Instead of supporting people at a time of great difficulty with dementia often we are doing harm through poor care and social avoidance.

A diagnosis of dementia should not rob any Australian of the opportunity to engage in social activities or to health care. The community’s lack of understanding about dementia and how best to respond leads to social isolation and discrimination.

In my speech I talked about the results of a study by the University of Wollongong, and a Newspoll survey conducted on behalf of Eli Lilly. You can read about the results of this work below. This research highlights just how much further we have to go to educate the community and make Australia a dementia friendly country.

I am inclined to think that the best way of overcoming negativity is to be positive. The decision of the Commonwealth Government, subject to the agreement of the states and territories to make dementia a National Health Priority, is a great start. But being positive means a willingness to face the future with confidence and that means beating dementia through investment in dementia research and finding better treatments.

We all know that dementia research is grossly underfunded compared to other chronic diseases; over the last 10 years investment in dementia research by the National Health and Medical Research Council (NHMRC) has been one sixth that of cancer.

It is time that the government, through the NHMRC, provides dementia research with adequate funding. With additional funding we will be able to build research capacity for the future. We will also be able to invest in research projects that have the potential to better understand the cause of dementia and ways of delaying its progression so we lead dementia free lives.

There is good evidence to show that investment in research is the best way to mitigate escalating health and aged care costs. Research provides the best chance to find better ways to prevent and treat dementia, reduce the numbers of people with dementia and have a chance at ultimately finding a cure.

Thank you for your support for our Fight Dementia Campaign. I take every opportunity to discuss the importance of the next phase of our campaign and to work towards a world without dementia by investment in dementia research.

Overall it was a very successful week for increasing the awareness of dementia in Australia.

My very best wishes to you all,

Ita Buttrose
National President
Alzheimer’s Australia
“Exploring Dementia and Stigma Beliefs” describes the results of a pilot study which asked 616 Australians for their views about people with dementia. The study was conducted by Lyn Phillipson and colleagues at the Centre for Health Initiative at the University of Wollongong.

50.8% of the respondents agreed that people with dementia cannot be expected to have a meaningful conversation, and 11.7% of respondents said that they would avoid spending much time with a person who had dementia.

Additionally, a percentage of respondents agreed that people with dementia:

• can be irritating – 30.4%;
• have poor personal hygiene – 14.3%.

However, there were some positive views expressed with the following percentage of respondents agreeing that people with dementia:

• are able to participate in a wide variety of activities – 38.6%;
• are a good source of wisdom – 37.7%;
• can pass on valued traditions – 34.4%.

The results also indicate that there is an expectation by many in the community that if they receive a diagnosis of dementia they would feel a sense of shame or humiliation or experience depression or anxiety. Many were also afraid that a diagnosis would mean that they would be discriminated against both in the community and in the health sector.

Alzheimer’s Australia is committed to raising awareness about dementia and reducing the stigma and social isolation that often accompanies a diagnosis.

For a copy of the report, click here.
WHAT THE PBAC REVIEW MEANS TO YOU

Thank you to all our Champions who responded to our Campaign Alert about the Pharmaceutical Benefits Advisory Committee review of medications for dementia.

We were concerned about the review and what it could mean for individuals living with dementia. So, with the help of our National President we took action. As well as asking our Champions for their opinions, Ita sent tweets to alert her 19,000 Twitter followers to the review. Our Campaign Team also alerted Alzheimer’s Australia’s 10,000 Facebook followers.

As a result of our activity we have received many heartfelt messages, filled with concern, which told us how important these medications were for both the person with dementia and their families.

Here are just a few messages that Alzheimer’s Australia has received over the past month:

I am a pensioner and thus have limited financial resources. Finding out that the Federal Government is considering ending my access to Aricept under PBS is my worst nightmare. PLEASE DO NOT DO THIS! It will be very difficult to afford my anti-dementia medication and if the government ends any PBS payments, my eventual decline and death will be hastened by this decision.

Leo

My Husband was diagnosed with Fronto-temporal dementia and was put on Aricept immediately. He continued with this medication until his death 5 ½ years later. In addition he was medicated with Ebixa (not on the PBS at that stage) for about his last 2 years...tests found that together with the Fronto-temporal dementia he had, very unusually, Alzheimer’s changes in the brain which the researchers said occurred later than the Fronto-temporal dementia. Had my Husband not have continued taking the Aricept and Ebixa medications, he may well have exhibited memory changes, loss of understanding language, behavioural changes etc and thus a reduced quality of life for him and far greater stress for myself as primary carer and all our family.

Lucille

Medication already costs up to $250 per month. If Aricept is taken off the PBS we will not be able to afford it.

Judy

I object in the strongest terms that the government could think about doing this. The financial impact would be enormous on us personally.

Denise

If you would like to read more of the messages sent to us, click here.

A RUNDOWN ON THE SUBMISSION

Your messages helped shape our submission to the review, which was provided to the Committee on Friday 6 July.

Here is a summary of what we recommended:

1. The Committee should consider equally both the benefits of the medications and the cost effectiveness of subsidising them.

2. The current rules for continuation of medications beyond six months should be revised to allow a clinician to determine the effectiveness of the medications. This rule has been recommended and is being practised in the UK.

3. Strategies should be put in place to ensure better management of medications, particularly focusing on reducing concurrent prescription of anti-dementia medications, which often results in the two medications cancelling each other out.

4. Examination of the current prescribing practices of antipsychotic medications for people with dementia, with a view to reducing rates of prescription.

If you would like to read a copy of our submission, click here.

UPCOMING EVENT

At the 7th Annual Mind & Its Potential conference you will have the opportunity to hear from 35+ international and local speakers and enjoy their potent mix of cutting edge research, philosophical, scientific and social perspectives and inspiring personal stories.

Date: 29 – 30 October 2012

Location: Sydney Convention and Exhibition Centre

For more information, click here.

CONTACT US

For further information on the campaign please visit the campaign website at http://campaign.fightdementia.org.au/ or email fightdementia@alzheimers.org.au

To opt out of receiving this e-newsletter please send an email to fightdementia@alzheimers.org.au with OPT OUT in the subject.