DEMENTIA FRIENDLY COMMUNITIES AND ORGANISATIONS IN AUSTRALIA

I WOULD LIKE TO ACKNOWLEDGE THE TRADITIONAL OWNERS OF THE LAND ON WHICH WE ARE MEETING AND PAY MY RESPECT TO ELDERS PAST AND PRESENT.

I AM DELIGHTED TO BE ABLE TO SPEAK WITH YOU THIS AFTERNOON AND I WOULD LIKE TO THANK THE ORGANISERS FOR THE OPPORTUNITY TO TALK ABOUT THE WORK WE ARE PIONEERING IN REGARDS TO CREATING DEMENTIA FRIENDLY COMMUNITIES.

THE CONCEPT OF DEMENTIA FRIENDLY COMMUNITIES IS A SIMPLE ONE. IT IS ABOUT DEVELOPING WAYS TO PROMOTE SOCIAL INCLUSION AS WELL AS AWARENESS ABOUT DEMENTIA. IT’S WHERE A SOCIETY CONSCIOUSLY ACTS TO ENSURE THAT PEOPLE WITH DEMENTIA ARE EMBRACED INTO THE COMMUNITY AND THEIR NEEDS ARE ADDRESSED ACROSS THE PHYSICAL AND SOCIAL ENVIRONMENT.

THE IDEA IS GAINING INTERNATIONAL MOMENTUM WITH INNOVATIVE WORK OCCURRING IN THE UNITED KINGDOM AND BELGIUM. I AM PLEASED THAT WE NOW HAVE THE OPPORTUNITY TO IMPLEMENT THE CONCEPT HERE IN AUSTRALIA.
There are more than 320,000 Australians with dementia and whilst dementia is not a natural part of ageing and affects 24,000 people under the age of 65, age is the biggest risk factor for dementia. About 30 percent of those over 85 years have dementia.

The rapid ageing of the population means that the number of people with dementia in Australia will increase. By 2050 there will be nearly 900,000 Australians with dementia.

There are already 1.2 million people involved in caring for a person with dementia. Dementia is not just a medical condition, it also has profound social implications.

Often people just associate dementia with memory changes and forget how it can affect behaviours, communication, relationships and the ability to undertake everyday tasks.

We know, from talking and listening to Australians living with dementia that social isolation and stigma are two of the biggest challenges they face in every day life.

People often find that family and friends stop calling or visiting after they hear of a diagnosis.

A study last year showed that 60 per cent of those surveyed indicated that if they received a diagnosis of dementia they would
FEEL A SENSE OF SHAME, AND NEARLY HALF SAID THAT THEY WOULD BE HUMILIATED BY THE DIAGNOSIS.

APPROXIMATELY 1 IN 5 SAID THEY WOULD FEEL UNCOMFORTABLE SPENDING TIME WITH A PERSON WHO HAD DEMENTIA.

IT IS UNACCEPTABLE FOR PEOPLE TO LIVE IN SHAME AND BE ISOLATED FROM THEIR COMMUNITY BECAUSE THEY HAVE A MEDICAL DIAGNOSIS OF DEMENTIA.

IN MY VIEW, PROMOTING ACTIVE SOCIAL ENGAGEMENT IN THE COMMUNITY BY PEOPLE WITH DEMENTIA AND THEIR CARERS IS THE BEST WAY TO ENSURE A BETTER UNDERSTANDING OF DEMENTIA AND ALSO TO DISPEL SOME OF THE MYTHS.

I BELIEVE THE EXPERIENCE AND ADVICE OF PEOPLE LIVING WITH DEMENTIA IS FUNDAMENTAL TO THE DEVELOPMENT OF DEMENTIA FRIENDLY COMMUNITIES IN AUSTRALIA. WE HAVE RECENTLY ESTABLISHED A DEMENTIA ADVISORY GROUP AND ONE OF THEIR TASKS WILL BE TO SUPPORT THIS WORK TO MAKE SURE WE GET IT RIGHT.

WE ARE COMMITTED TO ACHIEVING SOCIAL CHANGE BY WORKING WITH COMMUNITIES TO LISTEN TO THE NEEDS OF PEOPLE LIVING WITH DEMENTIA. TO HEAR THEIR VIEWS ABOUT HOW COMMUNITIES AND ORGANISATIONS CAN MAKE THEIR JOURNEY EASIER. TO CREATE OPPORTUNITIES TO REMAIN ENGAGED WITHIN SOCIETY AND TO CONTRIBUTE IN A MEANINGFUL AND SUPPORTED WAY.
A WONDERFUL EXAMPLE OF THIS IS THE WORK THAT HAS BEEN UNDERTAKEN THROUGH LIFECARE IN SOUTH AUSTRALIA. LIFECARE PILOTED THE SIDE BY SIDE PROGRAM WHICH SUPPORTS PEOPLE LIVING WITH DEMENTIA TO PARTICIPATE IN THE WORKPLACE AT BUNNINGS. EACH PERSON LIVING WITH DEMENTIA WAS SUPPORTED TO ENGAGE IN WORK THEY WERE INTERESTED IN WITH A WORK PLACE BUDDY. FOR ME, CREATING DEMENTIA FRIENDS IN THE WORKPLACE AND PROVIDING THEM WITH APPROPRIATE EDUCATION AND TRAINING IS A POWERFUL STRATEGY TO HELP REDUCE SOME OF THE STIGMA THAT EXISTS IN SOCIETY TODAY.

THE WORDS OF THE PEOPLE WITH DEMENTIA INVOLVED IN THE PROJECT EXPLAIN IT BETTER THAN I CAN.

“I WANT TO KEEP DOING THINGS THAT ARE USEFUL”

“FEELING OF DOING SOMETHING WORTHWHILE AGAIN”

“ACHIEVE A SENSE OF PURPOSE”

ANOTHER EXAMPLE OF AN ORGANISATION INCORPORATING THE NEEDS OF PEOPLE WITH DEMENTIA AND RAISING AWARENESS IS THE NATIONAL GALLERY OF AUSTRALIA. WORKING IN PARTNERSHIP WITH ALZHEIMER’S ACT, THE GALLERY HAVE DEVELOPED A SPECIALISED PROGRAM TO ENABLE PEOPLE LIVING WITH DEMENTIA TO ENJOY THE GALLERY WITH THE SUPPORT OF ALZHEIMER’S ACT STAFF AND TRAINED GUIDES.
ALZHEIMER’S AUSTRALIA WA HAS A PROGRAM WHERE THEY SUPPORT PEOPLE WITH DEMENTIA TO VOLUNTEER IN THE COMMUNITY AND ARE ACCOMPANIED BY A “VOLUNTEER BUDDY”. FOR EXAMPLE, ONE PERSON WITH YOUNGER ONSET DEMENTIA HELPS OUT OLDER PEOPLE IN HIS COMMUNITY WITH THEIR GARDENS. HE RECENTLY SPOKE ABOUT HOW THE CHANCE TO CONNECT WITH THE PEOPLE HE IS HELPING HAS MADE SUCH A DIFFERENCE TO HIM AND TO THE OLDER PEOPLE AS WELL.

THE STILL TICKING MEN’S GROUP FUNDED BY ACT GOVERNMENT IS A WONDERFUL PROGRAM FOR MEN WITH DEMENTIA. STILL TICKING IS AN ACTIVE GROUP THAT VISIT MANY DIFFERENT EXHIBITIONS IN THE ACT. THEY ALSO HAVE THE OCCASIONAL TRIP TO THE BEACH OR THE BUSH FOR LUNCH.

THE CONCEPT OF DEMENTIA FRIENDLY COMMUNITIES BUILDS ON THESE EXISTING INITIATIVES. EARLIER THIS YEAR, OUR PRESIDENT, ITA BUTTROSE, LAUNCHED TWO PUBLICATIONS THAT DISCUSS OUR PRIORITIES AND OUTLINE OUR DIRECTION AROUND DEMENTIA FRIENDLY COMMUNITIES.

THE FIRST PAPER, DEMENTIA-FRIENDLY SOCIETIES: THE WAY FORWARD OUTLINES AN ACTIVE APPROACH TO BETTER ENGAGE PEOPLE WITH DEMENTIA
IN OUR COMMUNITIES. IT IS ABOUT TREATING PEOPLE EQUALLY AND WITH RESPECT REGARDLESS OF THEIR AGE, GENDER OR DISABILITY.

WALKING GROUPS, CHOIRS, SCHOOL PROGRAMS, VISITS TO ART GALLERIES, WORKPLACE ENGAGEMENT PROGRAMS, COMMUNITY STAFF TRAINING, THE USE OF ASSISTIVE TECHNOLOGY AND IMPROVED STREET SCAPES ARE ALL BUILDING BLOCKS TO ACHIEVING A DEMENTIA FRIENDLY COMMUNITY.

AN EXAMPLE OF THE IMPORTANCE OF THIS APPROACH IS WITH REGARD TO TRANSPORT. ONE OF THE FIRST CONSEQUENCES FOR A PERSON WITH DEMENTIA OF A DIAGNOSIS – AND ONE OF THE MOST TRAUMATIC - IS THE LOSS OF THEIR DRIVING LICENCE. NOT ONLY CAN THIS BE HUMILIATING FOR A LIFE LONG DRIVER BUT IT CREATES DEPENDENCE ON OTHERS FOR TRANSPORT. AT THE SAME TIME, PEOPLE WITH DEMENTIA CAN FIND CATCHING PUBLIC TRANSPORT CONFUSING AND CONFRONTING.

IT IS AN IMPORTANT EXAMPLE OF THE IMPORTANCE OF TRAINING FOR BUS DRIVERS, TAXI DRIVERS AND EMERGENCY WORKERS IN UNDERSTANDING DEMENTIA AND COMMUNICATING WITH PEOPLE WITH DEMENTIA. ALZHEIMERS AUSTRALIA HAS DEVELOPED A SET OF DVDS THAT ARE DESIGNED TO HELP TRAIN THESE WORKERS AS WELL AS OTHERS IN BANKING AND RETAILING. THESE CAN BE FOUND AT ISITDEMENTIA.ORG.AU.
I am pleased that just last month the NSW Government announced a roll out of dementia training for all of their transport staff based on this resource.

It is exciting that the concept of dementia friendly communities is gaining grass-roots momentum even within Australia. For example, there was just recently an announcement in Port Macquarie, where members of the local community have identified the pressing need to be more dementia friendly and are developing a plan, in consultation with people living with dementia, to address their needs. We will link in and support these local initiatives as they evolve.

The second report, Cognitive Impairment Symbol: Creating Dementia Friendly Organisations is based on an idea that was first raised by consumers at the Alzheimer’s Australia 2005 National Consumer Summit.

It refers to the idea of a cognitive impairment symbol. The symbol will serve to identify organisations such as banks and Centrelink that have made a commitment to train and educate staff about dementia and on the best way to communicate with individuals who have a cognitive impairment.
IN THE COMING MONTHS, WORKING CLOSELY WITH THE COMMUNITY AND PEOPLE WITH DEMENTIA WE WILL BE DEVELOPING GUIDING PRINCIPLES FOR DEMENTIA FRIENDLY ORGANISATIONS. WE WILL WORK CLOSELY WITH NATIONAL ORGANISATIONS TO ASSIST THEM IN BECOMING MORE DEMENTIA FRIENDLY AND WILL BE GUIDED BY THE KNOWLEDGE AND EXPERIENCE OF PEOPLE LIVING WITH DEMENTIA.

THE FOCUS AT THIS CONFERENCE TODAY HAS PREDOMINATELY BEEN ON AGEING WELL WITHIN ONES COMMUNITY AND I CHALLENGE YOU TO THINK ABOUT HOW PEOPLE WITH DEMENTIA CAN ALSO LIVE WELL WITHIN THEIR COMMUNITIES. I AM ENCOURAGED ABOUT THE SYNERGIES BETWEEN THE WORK WE ARE PLANNING AND THE OTHER INITIATIVES DISCUSSED HERE TODAY.

THE NEXT STEP AND MAKE THE LIVES OF PEOPLE LIVING WITH DEMENTIA JUST THAT BIT EASIER.

THE OPPORTUNITIES AND THE CHALLENGE ARE OURS TO EMBRACE.

I ONCE AGAIN THANK YOU FOR THE OPPORTUNITY.