

**DEMENTIA-FRIENDLY COMMUNITIES - INVOLVING PEOPLE WITH DEMENTIA  
RACHAEL LITHERLAND WORKSHOP**

**PRINCE HENRY CENTRE  
2 COAST HOSPITAL ROAD, LITTLE BAY, SYDNEY**

**3 APRIL 2014**

**ITA BUTTROSE AO, OBE  
NATIONAL PRESIDENT – ALZHEIMER'S AUSTRALIA**

**GOOD AFTERNOON AND WELCOME EVERYONE. THANK YOU FOR BEING HERE TODAY. I AM DELIGHTED TO OPEN THIS IMPORTANT DISCUSSION ABOUT DEMENTIA-FRIENDLY COMMUNITIES.**

**ALZHEIMER'S AUSTRALIA IS GRATEFUL RACHAEL THAT YOU HAVE BEEN ABLE TO COME TO AUSTRALIA TO TELL US ABOUT YOUR WORK IN THE UK IN DEVELOPING DEMENTIA-FRIENDLY COMMUNITIES AND SUPPORTING PEOPLE WITH DEMENTIA TO BE ENGAGED IN ORGANISATIONS AND THE COMMUNITY AT LARGE.**

**I'M HOPEFUL THAT TODAY'S WORKSHOP WILL BOTH INFORM AND INSPIRE PEOPLE ABOUT THE ACTION THEY, AS INDIVIDUALS, CAN EACH TAKE IN THEIR LOCAL COMMUNITIES.**

**IN NSW ALONE THERE ARE MORE THAN 100,000 PEOPLE LIVING WITH DEMENTIA. THIS NUMBER IS EXPECTED TO INCREASE TO MORE THAN 300,000 BY 2050. IN THE AREA OF RANDWICK ALONE THERE ARE ALMOST 2000 PEOPLE LIVING WITH DEMENTIA.**

**WE OFTEN TALK ABOUT THE IMPLICATIONS OF THE RAPID INCREASE IN PEOPLE WITH DEMENTIA ON THE HEALTH AND CARE SYSTEM, BUT IT'S EQUALLY IMPORTANT TO DISCUSS WHAT THIS MEANS IN TERMS OF THE IMPACT ON RELATIONSHIPS, SOCIAL LIVES, AND QUALITY OF LIFE FOR PEOPLE LIVING WITH DEMENTIA.**

**JUST RECENTLY, AMERICAN ACTOR, SETH ROGEN, TESTIFIED BEFORE THE U.S. SENATE ABOUT THE IMPORTANCE OF DEMENTIA CARE AND SUPPORT, AND INVESTMENT IN RESEARCH.**

**SOMETHING HE SAID CAUGHT MY ATTENTION. "AMERICANS WHISPER THE WORD ALZHEIMER'S BECAUSE THEIR GOVERNMENT WHISPERS THE WORD ALZHEIMER'S. AND ALTHOUGH A WHISPER IS BETTER THAN THE SILENCE THAT THE ALZHEIMER'S COMMUNITY HAS BEEN FACING FOR DECADES, IT IS STILL NOT ENOUGH. IT NEEDS TO BE YELLED AND SCREAMED TO THE POINT THAT IT FINALLY GETS THE ATTENTION AND THE FUNDING THAT IT DESERVES AND NEEDS."**

**AND OF COURSE THAT IS WHY ALZHEIMER'S AUSTRALIA STARTED THE FIGHT DEMENTIA CAMPAIGN IN OCTOBER 2011 WITH A MARCH ON PARLIAMENT HOUSE IN CANBERRA**

**I THINK SETH'S WORDS CAPTURE WELL THE STIGMA AND SOCIAL ISOLATION THAT 332,000 AUSTRALIANS WITH DEMENTIA AND THEIR FAMILIES AND CARERS ARE FACED WITH ALMOST EVERY DAY.**

**IT IS THIS SILENT TYPE OF DISCRIMINATION THAT WE'RE TRYING TO TACKLE WITH THE DEMENTIA-FRIENDLY INITIATIVE.**

**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 OF DEMENTIA. MOST PEOPLE IN THE COMMUNITY DON'T UNDERSTAND DEMENTIA AND SO WHEN A PERSON BEHAVES A LITTLE DIFFERENTLY OR NEEDS ADDITIONAL THEY AVOID SOCIAL CONTACT.**

**I BELIEVE IT'S RARE THAT THE HURT THIS CAUSES IS DELIBERATE; IT IS THE RESULT OF IGNORANCE AND SOCIAL AWKWARDNESS AND THE UNCERTAINTY ABOUT HOW TO RESPOND AND COMMUNICATE WITH A PERSON WHO HAS DEMENTIA.**

**RESEARCH ALZHEIMER'S AUSTRALIA COMMISSIONED IN 2012 SHOWED THAT 60 PER CENT OF THOSE SURVEYED INDICATED THAT IF THEY RECEIVED A DIAGNOSIS OF DEMENTIA THEY WOULD FEEL A SENSE OF SHAME. NEARLY HALF SAID THAT THEY WOULD BE HUMILIATED BY THE DIAGNOSIS.**

**AND MORE THAN HALF INDICATED THAT PEOPLE WITH DEMENTIA CAN'T BE EXPECTED TO HAVE A MEANINGFUL CONVERSATION.**

**MORE THAN A THIRD SAID THAT PEOPLE WITH DEMENTIA COULD BE IRRITATING AND ONE IN 10 ADMITTED THEY WOULD AVOID SPENDING TIME WITH A PERSON WITH DEMENTIA.**

**JUST IMAGINE HOW ISOLATING IT MUST BE TO FEEL A SENSE OF SHAME BECAUSE OF A MEDICAL DIAGNOSIS OF DEMENTIA.**

**DEMENTIA-FRIENDLY COMMUNITIES CHALLENGE THIS STIGMA AND OFFER THE OPPORTUNITY TO PROMOTE BROADER AWARENESS ABOUT DEMENTIA AND SOCIAL ENGAGEMENT OF PEOPLE WITH DEMENTIA IN COMMUNITIES THROUGHOUT AUSTRALIA.**

**SO WHAT IS A DEMENTIA-FRIENDLY COMMUNITY? IT IS ONE THAT SUPPORTS PEOPLE LIVING WITH DEMENTIA TO BE EMPOWERED, RESPECTED, SUPPORTED AND ENGAGED IN ALL ASPECTS OF COMMUNITY LIFE. IT IS ABOUT WORKING WITH ORGANISATIONS SO THAT THEY CAN BETTER MEET THE NEEDS OF PEOPLE WITH DEMENTIA.**

**AND I'M NOT JUST TALKING ABOUT CARE AND SUPPORT ORGANISATIONS; BUT LIBRARIES AND GALLERIES, SPORT AND LEISURE FACILITIES, CAFES AND PUBLIC TRANSPORT... IT'S ABOUT SUPPORTING PEOPLE WITH DEMENTIA TO BE INVOLVED OR REMAIN INVOLVED IN VOLUNTEERING AND EMPLOYMENT OPPORTUNITIES.**

**IT IS ABOUT BUSINESSES PROVIDING BETTER SERVICES TO PEOPLE WITH DEMENTIA BECAUSE THEY HAVE TRAINED STAFF THAT UNDERSTANDS WHAT DEMENTIA IS AND HOW IT IMPACTS PEOPLE'S LIVES.**

**ALL OF THESE INITIATIVES ARE THE BUILDING BLOCKS OF A DEMENTIA-FRIENDLY COMMUNITY.**

**THERE ARE ALREADY WONDERFUL EXAMPLES OF COMMUNITIES EMBRACING THE DEMENTIA-FRIENDLY CONCEPT IN AUSTRALIA.**

**FOR INSTANCE, ALZHEIMER'S AUSTRALIA IN SOUTH AUSTRALIA DEVELOPED A SET OF TRAINING RESOURCES FOR FRONT-LINE STAFF WHO WORK IN PROFESSIONS WHERE THEY ARE LIKELY TO INTERACT WITH PEOPLE WHO HAVE DEMENTIA. THE *IS IT DEMENTIA* RESOURCE IS A SET OF VIDEOS TARGETED AT EMERGENCY WORKERS, STAFF IN BANKS, RETAIL STAFF AND COMMUNITY SERVICES.**

**THE VIDEOS DEPICT SOME OF THE BEHAVIOURS THAT SOMEONE WITH DEMENTIA MAY PORTRAY IN CERTAIN SITUATIONS IN THE COMMUNITY. THE RESOURCE HELPS PEOPLE IN THESE PROFESSIONS TO DETERMINE IF SOMEONE MAY HAVE DEMENTIA.**

**NSW TRANSPORT HAS ALREADY BEGUN USING THIS RESOURCE TO TRAIN THE PUBLIC TRANSPORT STAFF IN THIS STATE.**

**IN PORT MACQUARIE, THERE HAS BEEN GRASSROOTS INTEREST IN THE CONCEPT OF DEMENTIA-FRIENDLY COMMUNITIES. WITH LEADERSHIP FROM THEIR LOCAL MP, LESLIE WILLIAMS.**

**THE COMMUNITY HAS BROUGHT TOGETHER A DEMENTIA ACTION GROUP MADE UP OF REPRESENTATIVES FROM LOCAL GOVERNMENT, POLICE, CHURCHES, AND OTHER COMMUNITY ORGANISATIONS TO TALK ABOUT HOW THEY CAN MAKE PORT MACQUARIE A BETTER PLACE FOR PEOPLE WITH DEMENTIA TO LIVE.**



**OTHER EXCELLENT PROGRAMS HAPPENING ACROSS AUSTRALIA INCLUDE DEMENTIA-CHOIRS, EVENTS AT ART GALLERIES, WALKING GROUPS AND VOLUNTEERING OPPORTUNITIES.**

**ALL OF THESE INITIATIVES HELP PROVIDE A PLATFORM ON WHICH WE CAN BUILD TO CREATE MORE DEMENTIA-FRIENDLY COMMUNITIES AND ORGANISATIONS**

**WHEN WORKING FOR SOCIAL CHANGE IT'S IMPORTANT TO SET ACHIEVABLE BUT CHALLENGING GOALS. SO ALZHEIMER'S AUSTRALIA IS NO LONGER JUST CALLING FOR "DEMENTIA-FRIENDLY COMMUNITIES" BUT RATHER FOR THE CREATION OF A DEMENTIA-FRIENDLY AUSTRALIA.**

**IN FEBRUARY THIS YEAR I LAUNCHED ALZHEIMER'S AUSTRALIA'S NEW FIGHT DEMENTIA CAMPAIGN DOCUMENT, "*CREATING A DEMENTIA-FRIENDLY AUSTRALIA*". THE DOCUMENT WAS DEVELOPED WITH INPUT FROM PEOPLE WITH DEMENTIA AND THEIR CARERS. AND OUTLINES OUR VISION FOR THE NEXT THREE YEARS ON WHAT SHOULD BE DONE TO ACHIEVE A DEMENTIA-FRIENDLY NATION... AN AUSTRALIA WHERE PEOPLE WITH DEMENTIA RECEIVE THE RESPECT AND ACCESS TO SERVICES THAT WE ALL EXPECT.**

**WE ARE SEEKING BIPARTISAN SUPPORT OVER THE NEXT THREE YEARS TO DEVELOP AND IMPLEMENT FIVE IMPORTANT INITIATIVES.**

**FIRSTLY, \$5 MILLION TO DEVELOP A NATIONAL DEMENTIA-FRIENDLY COMMUNITIES INITIATIVE.**

**WE ARE BECOMING INCREASINGLY AWARE THAT NO MATTER HOW MUCH GOOD WILL THERE IS IN THE COMMUNITY, WE NEED RESOURCES ON THE GROUND TO DEVELOP DEMENTIA-FRIENDLY COMMUNITIES AND TO TACKLE THE SOCIAL ISOLATION THAT DEMENTIA BRINGS WITH IT.**

**THIS INVESTMENT WOULD HAVE A HUGE MULTIPLIER EFFECT BECAUSE OF THE BROAD COMMUNITY INTEREST AND WOULD HAVE A MUCH LARGER IMPACT THAN A \$5 MILLION ADVERTISING OR AWARENESS CAMPAIGN.**

**SECONDLY, THE DEVELOPMENT OF A NATIONAL PROGRAM OF DEMENTIA ADVISORS.**

**PEOPLE WITH DEMENTIA WANT SUPPORT AND GUIDANCE THROUGHOUT THEIR JOURNEY. THE FEDERAL GOVERNMENT HAS SUPPORTED A KEY WORKER PROGRAM FOR PEOPLE WITH YOUNGER ONSET DEMENTIA, AND IT IS TRULY INSPIRING TO HEAR THE STORIES OF WHAT A DIFFERENCE THE KEY WORKERS ARE MAKING IN THE LIVES OF PEOPLE WITH DEMENTIA.**

**WE ARE ASKING THE GOVERNMENT TO BUILD ON THIS IMPORTANT INITIATIVE – INITIALLY TO PROVIDE THE SERVICE TO PEOPLE FROM VULNERABLE GROUPS SUCH AS THOSE FROM DIVERSE BACKGROUNDS, THE HOMELESS AND PEOPLE LIVING ALONE. BUT OUR LONG TERM VISION IS A NATIONAL PROGRAM OF KEY WORKERS WHO CAN SUPPORT ALL PEOPLE WITH DEMENTIA.**

**THIRDLY, THE EXPANSION OF DEMENTIA-SPECIFIC RESPITE WHICH IS SO IMPORTANT FOR THE ESTIMATED 1.2 MILLION AUSTRALIANS INVOLVED IN THE CARE OF SOMEONE WITH DEMENTIA.**

**RESPITE PROVIDES A CARER WITH A MUCH-NEEDED BREAK AND GIVES THE PERSON WITH DEMENTIA THE OPPORTUNITY FOR SOCIAL INTERACTION. YET IN SPITE OF ITS SIGNIFICANCE, TOO OFTEN RESPITE CARE FACILITIES ARE ILL-EQUIPPED TO PROVIDE SERVICES FOR PEOPLE WITH BEHAVIOURAL AND PSYCHOLOGICAL SYMPTOMS OF DEMENTIA. WHAT'S MORE, THE SERVICES ARE OFTEN NOT AVAILABLE WHERE AND WHEN THEY ARE NEEDED.**

**FOURTHLY, TO IMPROVE THE QUALITY OF RESIDENTIAL CARE.**

**MOST PEOPLE WANT TO STAY IN THE COMMUNITY FOR AS LONG AS THEY CAN BUT OFTEN BECAUSE OF HIGH CARE NEEDS, PEOPLE WITH DEMENTIA HAVE TO MOVE INTO RESIDENTIAL CARE.**

**FAMILIES AND CARERS OF PEOPLE WITH DEMENTIA SHOULD HAVE CONFIDENCE THAT THEIR LOVED ONES WILL BE GIVEN THE HIGH QUALITY CARE THAT WE WOULD EXPECT FOR ALL AUSTRALIANS.**

**LASTLY, THE IMPLEMENTATION OF A NEW NATIONAL ACTION FRAMEWORK ON DEMENTIA.**

**WE NEED TO ENSURE THAT THERE IS A COHERENT APPROACH TO TACKLING DEMENTIA ACROSS THE STATES AND TERRITORIES. A NEW FRAMEWORK WOULD PROVIDE THE OPPORTUNITY TO PRIORITISE ACTION IN REGARDS TO TIMELY DIAGNOSIS, CARE IN HOSPITALS, END-OF-LIFE CARE AND RISK REDUCTION.**

**YOU NOW KNOW WHAT OUR VISION IS FOR THE NEXT THREE YEARS IN TERMS OF GOVERNMENT ACTION BUT AS A COMMUNITY, WE CAN'T JUST RELY ON GOVERNMENT TO IMPROVE SUPPORT FOR PEOPLE WITH DEMENTIA.**

**WE NEED TO TAKE RESPONSIBILITY FOR MAKING OUR COMMUNITIES A PLACE WHERE WE WOULD WANT TO LIVE IF WE HAD DEMENTIA. OFTEN IT IS JUST THE SMALL THINGS THAT CAN MAKE SUCH A DIFFERENCE... A DEMENTIA-FRIENDLY CAFE, WHERE THE STAFF ARE PATIENT IF A PERSON FUMBLES WITH THE CHANGE AS THEY TRY TO PAY OR AN ART GALLERY THAT HAS A SPECIAL PROGRAM FOR PEOPLE WITH DEMENTIA, OR A TAXI DRIVER THAT STOPS TO MAKE SURE THAT A PERSON WHO SEEMS CONFUSED HAS ARRIVED WHERE THEY NEED TO GO. NONE OF THESE SIMPLY GESTURES ARE DIFFICULT TO DO.**

**I HOPE YOU ENJOY RACHAEL'S TALK TODAY ABOUT THE GREAT WORK BEING DONE IN THE UK...I AM SURE YOU WILL.**

**BUT I ALSO WANT TO CHALLENGE YOU TO THINK ABOUT HOW YOU CAN TAKE WHAT YOU HEAR TODAY AND START MAKING SMALL CHANGES IN YOUR LOCAL COMMUNITY.**

**I WANT EACH OF YOU TO BE A CHAMPION FOR PEOPLE WITH DEMENTIA IN YOUR OWN COMMUNITY.**

**AND I'D LIKE TO THINK THAT ALL OF YOU ARE COMMITTED TO MAKING AUSTRALIA ONE OF THE WORLD'S FIRST DEMENTIA-FRIENDLY NATIONS.**

**THANK YOU.**