

**EDITH COWAN UNIVERSITY  
JOONDALUP, WA**

**AUSTRALIAN OF THE YEAR TOUR OF HONOUR WA 2013**

**18 JULY 2013**

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

**I AM PLEASED TO HAVE THE OPPORTUNITY TO TALK TO YOU THIS AFTERNOON IN MY ROLE AS AUSTRALIAN OF THE YEAR AND AS NATIONAL PRESIDENT OF ALZHEIMER'S AUSTRALIA.**

**BECOMING AUSTRALIAN OF THE YEAR IS NOT SOMETHING YOU EVER IMAGINE HAPPENING TO YOU. IT IS TRULY A GREAT HONOUR AND I AM CONSTANTLY REMINDED OF THE MANY DISTINGUISHED AUSTRALIANS IN WHOSE FOOTSTEPS I FOLLOW.**

**I AM GRATEFUL FOR THE PLATFORM IT GIVES ME TO TALK ABOUT ISSUES THAT I AM PASSIONATE ABOUT LIKE ALZHEIMER'S DISEASE AND OTHER DEMENTIAS.**

**MY AIM, AS I SAID, WHEN I ACCEPTED THE AWARD IN JANUARY THIS YEAR IS TO CONTRIBUTE THE BEST I CAN TO ACHIEVING A MORE POSITIVE APPROACH TO AGEING, PROVIDING OLDER AUSTRALIANS WITH A VOICE, DELIVERING ON ALZHEIMER'S AUSTRALIA'S FIGHT DEMENTIA CAMPAIGN AND PUTTING THE SPOTLIGHT ON MEDICAL RESEARCH.**

**THERE COULD BE NO BETTER TIME TO TALK ABOUT THESE ISSUES THAN DURING AN ELECTION PERIOD. AND FROM NOW UNTIL ELECTION DAY I WILL BE CALLING ON POLITICIANS ON BOTH SIDES OF POLITICS TO OUTLINE THEIR PLANS TO ADDRESS OUR COUNTRY'S DEMENTIA EPIDEMIC.**

**FOR ADVOCATES ELECTIONS ARE AN OPPORTUNITY FOR REFLECTION ON THE PAST AND PRIORITY SETTING FOR THE FUTURE.**

**SO LET ME GIVE YOU A BRIEF OUTLINE OF ALZHEIMER'S AUSTRALIA'S HISTORY. THREE YEARS AGO WE WERE ADVOCATING FOR GOVERNMENT TO BUILD ON THE 2005 DEMENTIA INITIATIVE IN A NUMBER OF WAYS SUCH AS RECOGNISING THE IMPORTANCE OF EARLY DIAGNOSIS AND ALSO ACUTE CARE AND RISK REDUCTION.**

**WE ASSUMED THE PRODUCTIVITY COMMISSION'S INQUIRY INTO THE CARE OF OLDER AUSTRALIANS WOULD BE HELPFUL IN PROMOTING LATERAL THINKING ON DEMENTIA IN BOTH HEALTH POLICY AND AGED CARE POLICY.**

**WE WERE WRONG TO MAKE THAT ASSUMPTION BECAUSE THE FIRST REPORT OF THE PRODUCTIVITY COMMISSION DID NOT MAKE A SINGLE RECOMMENDATION IN RESPECT OF DEMENTIA.**

**WHILE WE WELCOMED THE STRUCTURAL REFORMS THE COMMISSION PROPOSED TO THE AGED CARE SYSTEM WE WERE SURPRISED AND DISAPPOINTED THAT THERE WAS AN IMPLICIT ASSUMPTION THAT AGED CARE REFORM ALONE WOULD RESULT IN IMPROVED QUALITY OF DEMENTIA CARE.**

**WORSE STILL THE 2011 FEDERAL BUDGET, FAR FROM BUILDING ON THE DEMENTIA INITIATIVE, ABSORBED THE VARIOUS ELEMENTS INTO A NEW STRUCTURE OF DEPARTMENTAL FLEXIBLE FUNDING POOLS.**

**THESE DISAPPOINTMENTS CAUSED ALZHEIMER'S AUSTRALIA TO DRAMATICALLY RETHINK ITS ADVOCACY. WE TOOK OFF OUR VELVET GLOVE AND PUT ON OUR IRON FIST.**

**WE HAVE LEARNT TO BE AMBITIOUS WITHOUT FEAR ON BEHALF OF THE MORE THAN 320,000 AUSTRALIANS WITH DEMENTIA AND THEIR FAMILY CARERS.. THIS HAS INCLUDED MARCHING ON PARLIAMENT HOUSE, CANBERRA, INTENSE USE OF SOCIAL MEDIA AND THE RECRUITMENT OF NEARLY 50 FEDERAL SENATORS AND MEMBERS AS DEMENTIA CHAMPIONS.**

**OUR STRATEGY COMBINES MARKETING AND BRANDING, AND A FIGHT DEMENTIA CAMPAIGN THAT HAS SUCCEEDED IN LIFTING THE PROFILE OF ISSUES IN RELATION TO DEMENTIA.**

**THE SUCCESS OF OUR CAMPAIGN HAS BEEN DRIVEN BY THE STORIES OF PEOPLE WITH DEMENTIA AND FAMILY CARERS.**

**IN 2011, ALZHEIMER'S AUSTRALIA UNDERTOOK CONSULTATIONS ACROSS AUSTRALIA WITH PEOPLE WITH DEMENTIA AND THEIR FAMILY CARERS – WE ASKED THEM IF THE AGED CARE SYSTEM MET THEIR NEEDS – THEIR FEEDBACK DECISIVELY INFORMED THE GOVERNMENT THE EXTENT TO WHICH OUR HEALTH AND AGED CARE SYSTEM IS FAILING THEM.**

**THE RESULTING REPORT RELEASED IN APRIL 2012 ATTRACTED AN AUDIENCE OF 16 MILLION AUSTRALIANS.**

**I THINK IT IS IMPORTANT TO CAPTURE THIS STORY BECAUSE ALL TOO OFTEN IT IS ASSUMED THAT OUR POLITICIANS ARE NOT LISTENING.**

**IN MY EXPERIENCE THEY DO, BUT YOU HAVE TO BE PATIENT. TO BE A GOOD ADVOCATE YOU HAVE TO UNDERSTAND SUCCESS IS LIKE WATER DRIPPING ON A STONE.**

**DISAPPOINTMENT IN MID 2011 TRANSLATED INTO A SIGNIFICANT COMMITMENT TO TACKLING DEMENTIA WITHIN LAST YEAR'S *LIVING LONGER. LIVING BETTER.* AGED CARE REFORM PACKAGE WHICH BREAKS IMPORTANT NEW GROUND BY RECOGNISING THE IMPORTANCE OF TACKLING DEMENTIA WITHIN HEALTH POLICY AS WELL AS AGED CARE POLICY.**

**LAST AUGUST THE STANDING COUNCIL OF HEALTH MINISTERS RECOGNISED DEMENTIA AS A NATIONAL HEALTH PRIORITY AS PART OF THE REFORM PACKAGE.**

**THE COMMITMENT TO TACKLE DEMENTIA AS A HEALTH ISSUE HAS BEEN SUPPORTED BY ADDITIONAL FUNDING FOR DEMENTIA CARE IN HOSPITALS, TIMELY DIAGNOSIS AND FUNDING FOR ALZHEIMER'S AUSTRALIA'S RISK REDUCTION PROGRAM, YOUR BRAIN MATTERS.**

**WITHIN THE HOSPITAL INITIATIVE PROJECTS ARE BEING FUNDING TO:**

- **IMPROVE THE MANAGEMENT OF COGNITIVE IMPAIRMENT USING THE NATIONAL SAFETY AND QUALITY HEALTH SERVICE STANDARDS**
- **TO ENHANCE THE ENVIRONMENT AND DESIGN OF HOSPITALS FOR PEOPLE WITH COGNITIVE IMPAIRMENT**
- **UNDERTAKE AN AUDIT OF DEMENTIA TRAINING IN THE ACUTE SECTOR TO DETERMINE WHAT RESOURCES ARE AVAILABLE AND IDENTIFY GAPS;**
- **ADVISE ON ENVIRONMENTAL DESIGN IN ACUTE CARE**
- **PROMOTE CHANGE SUPPORT PROGRAMS BUILT ON EXISTING SYSTEMS WITHIN HOSPITALS TO IMPROVE CARE OUTCOMES OF PEOPLE WITH DEMENTIA THAT INCORPORATE A COST BENEFIT ANALYSIS.**

THERE IS ALSO IMPORTANT WORK GOING ON TO IDENTIFY THE TRAINING GPS AND NURSES NEED, DEMENTIA CARE PATHWAYS AND THE MEDICARE INCENTIVES NECESSARY TO ACHIEVE TIMELY DIAGNOSIS AND MANAGEMENT OF PATIENTS WITH DEMENTIA.

THE OTHER GROUND BREAKING PART OF THE *LIVING LONGER. LIVING BETTER.* PACKAGE WAS THE RECOGNITION OF THE EXTRA COSTS THAT DEMENTIA CARE REQUIRES. FROM AUGUST 1 THIS YEAR NEW DEMENTIA SUPPLEMENTS IN BOTH COMMUNITY AND RESIDENTIAL CARE WILL OPERATE.

IT WILL BE ESSENTIAL TO EVALUATE THE IMPACT OF THE SUPPLEMENTS AND ASSESS THE EXTENT TO WHICH THEY IMPROVE ACCESS TO CARE FOR THOSE PEOPLE WITH COGNITIVE IMPAIRMENT AND DEMENTIA.

I SUGGEST THIS BRIEF HISTORY OF RECENT YEARS SHOULD ENCOURAGE US TO CONTINUE TO BE AMBITIOUS WITHOUT FEAR OF FAILURE.

SO TODAY I AM RELEASING ALZHEIMER'S AUSTRALIA'S FIGHT DEMENTIA ELECTION DOCUMENT. THIS HAS BEEN REVISED TO TAKE INTO ACCOUNT THE IMPORTANT RECOMMENDATIONS MADE LAST MONTH BY THE HOUSE OF REPRESENTATIVES HEALTH AND AGEING COMMITTEE'S *THINKING AHEAD* REPORT.

**THE COMMITTEE'S 17 RECOMMENDATIONS GIVE PRIORITY TO PROMOTING AWARENESS OF DEMENTIA, EVIDENCE BASED TRAINING FOR DOCTORS, THE CASE FOR ESTABLISHING A DEMENTIA LINK WORKER PROGRAM AND THE CREATION OF DEMENTIA FRIENDLY COMMUNITIES AROUND AUSTRALIA.**

**AS NATIONAL PRESIDENT OF ALZHEIMER'S AUSTRALIA I SEE THREE MAJOR CHALLENGES OVER THE NEXT THREE YEARS.**

**THERE IS A NEED FOR A PROGRAM OF SOCIAL ACTION TO PROMOTE AWARENESS OF DEMENTIA AND ENGAGE PEOPLE WITH DEMENTIA IN THE LIFE OF OUR COMMUNITIES.**

**THERE IS A NEED TO MAKE FURTHER IMPROVEMENT IN THE QUALITY OF DEMENTIA CARE SERVICES BY BUILDING ON *LIVING LONGER. LIVING BETTER.***

**AND THERE IS AN URGENT NEED TO SECURE AND INCREASE INVESTMENT IN DEMENTIA RESEARCH OF \$200 MILLION OVER FIVE YEARS.**

**CONCLUSIVE EVIDENCE TELLS US THAT THAT PEOPLE WITH DEMENTIA EXPERIENCE STIGMA AND SOCIAL ISOLATION.**



**DEMENTIA IS STILL A CONDITION THAT IS ASSOCIATED WITH SHAME AND HUMILIATION. MANY AUSTRALIANS ARE NOT AWARE THAT DEMENTIA IS NOT A NORMAL PART OF AGEING.**

**A STUDY BY THE UNIVERSITY OF WOLLONGONG (NSW) LAST YEAR SHOWED THAT APPROXIMATELY ONE QUARTER OF THOSE SURVEYED WOULD AVOID SEEKING ASSISTANCE FOR MEMORY PROBLEMS. OF THOSE SURVEYED, 60 PER CENT INDICATED THAT IF THEY RECEIVED A DIAGNOSIS OF DEMENTIA, THEY WOULD FEEL A SENSE OF SHAME, AND NEARLY HALF SAID THEY WOULD BE HUMILIATED BY THE DIAGNOSIS OF DEMENTIA.**

**A 2011 NATIONAL POPULATION SURVEY REVEALED THAT MANY AUSTRALIANS WOULD FEEL UNCOMFORTABLE SPENDING TIME WITH SOMEONE WHO HAD DEMENTIA**

**ONE WAY TO BEGIN TO TACKLE THE STIGMA ASSOCIATED WITH DEMENTIA IS BY ENGAGING PEOPLE WITH DEMENTIA IN OUR COMMUNITIES.**

**AT OUR 15<sup>TH</sup> NATIONAL CONFERENCE EARLIER THIS YEAR, I LAUNCHED TWO PUBLICATIONS “DEMENTIA FRIENDLY SOCIETIES: THE WAY FORWARD” AND “COGNITIVE IMPAIRMENT SYMBOL: CREATING DEMENTIA FRIENDLY ORGANISATIONS”.**

**DEMENTIA FRIENDLY SOCIETIES IS AN IDEA THAT HAS ALREADY TAKEN ROOT OVERSEAS, ESPECIALLY IN THE UNITED KINGDOM AND BELGIUM.**

**I BELIEVE THE TIMING IS RIGHT FOR THIS CONCEPT TO BE IMPLEMENTED IN AUSTRALIA. ALZHEIMER'S AUSTRALIA WANTS TO ENCOURAGE CITIES AND TOWNS TO WORK WITH PEOPLE IN THEIR COMMUNITY, WHO HAVE DEMENTIA AND TO REFLECT ON HOW THEY CAN BE MORE DEMENTIA FRIENDLY.**

**WE CAN HELP PROMOTE THE ENGAGEMENT OF PEOPLE WITH DEMENTIA THROUGH A FOCUS ON BOTH THE SOCIAL AND PHYSICAL ENVIRONMENTS.**

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

**WE WANT THE GOVERNMENT TO COLLABORATE WITH US TO DEVELOP A SET OF FLEXIBLE VALUES AND STANDARDS WHICH WOULD INFORM THE CREATION OF DEMENTIA FRIENDLY COMMUNITIES AROUND AUSTRALIA.**

**AT THE SAME TIME, WE ALSO NEED DEMENTIA FRIENDLY ORGANISATIONS.**

**THE ESSENCE OF THIS IDEA IS THAT ORGANISATIONS COMMIT TO TRAIN THEIR STAFF TO UNDERSTAND DEMENTIA AND HOW TO COMMUNICATE WITH PEOPLE WHO MAY HAVE COGNITIVE IMPAIRMENT. A SYMBOL IS THEN DISPLAYED TO INDICATE THAT THE ORGANISATION HAS TRAINED STAFF WHO IS ABLE TO PROVIDE A DEMENTIA FRIENDLY SERVICE.**

**OUR CONSUMERS HAVE TOLD US FOR SOME YEARS NOW, THAT THEY WANTED A SYMBOL THAT COULD BE USED TO PROMOTE BETTER SERVICES AND SUPPORT FOR PEOPLE WITH DEMENTIA.**

**OF COURSE, IT IS UP TO THE INDIVIDUAL TO DECIDE WHETHER TO TAKE ADVANTAGE OF THIS SPECIAL SERVICE. NOT ALL PEOPLE WILL WANT TO DO SO. THAT'S THEIR CHOICE. THERE IS CERTAINLY NO QUESTION OF THE INDIVIDUAL HAVING TO WEAR THE SYMBOL.**

**BALLARAT HEALTH SERVICE HAS SUCCESSFULLY TAKEN THE LEAD OVER THE LAST 10 YEARS IN PROMOTING A COGNITIVE IMPAIRMENT IDENTIFIER THAT IS USED, WITH THE PERMISSION OF THE PATIENT AND THEIR FAMILY, TO DENOTE A PERSON WITH DEMENTIA IN HOSPITAL.**

**IN RETURN, HOSPITAL STAFF IS TRAINED TO BETTER UNDERSTAND DEMENTIA AND HOW TO COMMUNICATE TO PEOPLE WITH DEMENTIA.**

THERE ARE ALSO MECHANISMS TO COMMUNICATE WITH FAMILY CARERS TO HELP THEM OBTAIN THE NECESSARY INFORMATION TO CARE FOR THE PATIENT. THIS APPROACH IS NOW IN PRACTICE IN 22 HOSPITALS IN VICTORIA.

IT GOES TO THE HEART OF A MAJOR PROBLEM, NAMELY RECOGNISING PEOPLE WHO HAVE COGNITIVE IMPAIRMENT IN HOSPITALS WHO MAY BE SUBJECT TO GREAT RISK, FALLS, MALNUTRITION OR DELUSION.

AND IT'S IS NOT JUST IN THE HOSPITAL ENVIRONMENT THAT THE SYMBOL HAS POTENTIAL.

THERE ARE SO MANY SERVICE ENVIRONMENTS LIKE CENTRELINK FOR EXAMPLE, WHERE IT IS IMPORTANT FOR ORGANISATIONS TO MAKE A COMMITMENT TO A GOOD SERVICE FOR PEOPLE WITH COGNITIVE IMPAIRMENT. CENTRELINK IS VITAL FOR A PERSON WITH COGNITIVE IMPAIRED GETTING ACCESS TO ENTITLEMENTS.

TO HELP THESE ORGANISATIONS, ALZHEIMER'S AUSTRALIA SA WITH FUNDING FROM THE DEPARTMENT OF HEALTH AND AGEING CONSULTED WITH THE TRANSPORT, RETAIL, BANKING, CORRECTIONAL SERVICES, EMERGENCY SERVICES AND FIRE SERVICES TO DEVELOP 12 SHORT FILMS TITLED IS IT DEMENTIA? – A RESOURCE FOR RECOGNISING THE SIGNS OF DEMENTIA.

**THESE EDUCATIONAL RESOURCES WILL ASSIST A BETTER UNDERSTANDING OF DEMENTIA AND THE STRATEGIES THAT STAFF PROVIDING SERVICES CAN EMPLOY TO ENSURE THAT PEOPLE WITH DEMENTIA HAVE ACCESS TO SERVICES WE ALL NEED.**

**I WAS DELIGHTED TO LEARN AT OUR JUNE ALZHEIMER'S AUSTRALIA BOARD MEETING THAT THE ANZ IS ALREADY USING ALZHEIMER'S AUSTRALIA'S RESOURCE PACKAGE IN THEIR STAFF TRAINING PROGRAMS.**

**THE AGED CARE REFORMS AIM TO CREATE A SYSTEM WITH GREATER CHOICE AND FLEXIBILITY BUT THEY STOP SHORT OF THE ENTITLEMENT APPROACH RECOMMENDED BY THE PRODUCTIVITY COMMISSION. THEREFORE AGED CARE PLACES WILL CONTINUE TO BE RATIONED.**

**HOWEVER, THE *LIVING LONGER. LIVING BETTER* AGED CARE REFORMS OFFERS THE POSSIBILITY OF:**

- **84,000 EXTRA COMMUNITY CARE PLACES BY 2021**
- **ALL COMMUNITY CARE DELIVERED ON THE BASIS OF CONSUMER-DIRECTED CARE, AN APPROACH THAT MAKES POSSIBLE DECISION-MAKING BY THE OLDER PERSON AND THEIR FAMILIES ABOUT THEIR NEEDS**
- **GREATER INVESTMENT IN ASSESSMENT AND INFORMATION**
- **INTRODUCTION OF QUALITY INDICATORS THAT WILL MAKE THE ISSUES CONSUMERS HAVE ABOUT THE QUALITY OF CARE MORE TRANSPARENT**

**THIS IS GOOD NEWS. BUT WE DON'T WANT TO WAIT FOR ANOTHER THREE YEARS FOR A REVIEW OF THE OUTCOMES OF *LIVING LONGER. LIVING BETTER.* TO ADDRESS SOME OF THE SERIOUS CONCERNS WE HAVE NOW.**

**FOR INSTANCE, PEOPLE WITH YOUNGER ONSET DEMENTIA (YOD) NEED BETTER CARE TO BE AVAILABLE TO THEM. AT THE MOMENT MANY PEOPLE WITH YOUNGER ONSET DEMENTIA ARE PLACED IN AGED CARE FACILITIES BECAUSE THERE IS NO WHERE ELSE FOR THEM TO GO. THIS IS NOT GOOD ENOUGH.**

**THERE ARE ABOUT 25,000 PEOPLE UNDER 65 WITH DEMENTIA IN AUSTRALIA AND FOR MANY OF THEM TIMELY DIAGNOSIS AND ACCESS TO CARE AND SUPPORT SERVICES IS EXTREMELY DIFFICULT. MANY GPs DON'T EXPECT YOUNGER PEOPLE TO HAVE DEMENTIA AND A PROPER DIAGNOSIS SOMETIMES CAN TAKE YEARS.**

**AN INNOVATIVE ELEMENT OF *LIVING LONGER. LIVING BETTER'S* TACKLING DEMENTIA PACKAGE OFFERS SOME POSITIVE NEWS...WITH THE FUNDING OF 40 YOUNGER ONSET DEMENTIA KEY WORKERS THROUGH ALZHEIMER'S AUSTRALIA. SOME HAVE ALREADY STARTED WORK.**

**THEIR MAIN OBJECTIVE OF THESE WORKERS IS TO PROVIDE SUPPORT TO PEOPLE WITH YOUNGER ONSET DEMENTIA AND THEIR FAMILY CARERS, RANGING FROM INFORMATION TO ACCESSING SUPPORT AND CARE SERVICES. THEY WILL ALSO IDENTIFY SERVICE GAPS AND ASSIST SERVICE DEVELOPMENT.**

**INTERNATIONAL RESEARCH HAS SHOWN THAT KEY WORKER PROGRAMS FOR PEOPLE WITH DEMENTIA OF ALL AGES ARE COST EFFECTIVE AND LEAD TO REDUCED CARE GIVER BURDEN, REDUCED COST OF FORMAL CARE SERVICES AND REDUCED LIKELIHOOD OF ADMISSION TO RESIDENTIAL AGED CARE.**

**ULTIMATELY ALZHEIMER'S AUSTRALIA WOULD LIKE A COMMITMENT FROM ALL MAJOR POLITICAL PARTIES TO A NATIONAL KEY WORKER PROGRAM THAT WILL SUPPORT PEOPLE OF ALL AGES WITH DEMENTIA SO THAT THEY CAN HAVE THE CONFIDENCE THEY NEED TO ACCESS SERVICES AND AVOID THE MISUNDERSTANDING AND CONFUSION THAT MIGHT ARISE THROUGH A NATIONAL GATEWAY.**

**ALZHEIMER'S AUSTRALIA RECENTLY RELEASED A RESPITE REVIEW PAPER (IT CAN BE ACCESSED ON OUR WEBSITE).**

**WE HAVE ADVOCATED FOR THE CONCEPT OF RESPITE TO INCLUDE RECOGNITION OF THE BENEFIT TO THE OLDER PERSON OR PERSON WITH DEMENTIA.**

**WHY? WELL, THE REASON IS QUITE SIMPLE.**

**A PERSON WITH DEMENTIA ALSO NEEDS A BREAK AND ACCESS TO ACTIVITIES AND INTERESTS THAT MAY HAVE BEEN LIFE LONG. IT DOES NOT HELP THE FAMILY CARER IF THE PERSON WITH DEMENTIA RETURNS HOME MORE CONFUSED AND RESENTFUL ABOUT THE TIME THEY HAVE SPENT IN RESPITE BECAUSE THEIR INTERESTS HAVE NOT BEEN MET IN ANY WAY.**

**RESPITE CARE WILL NOT WORK FOR FAMILY CARERS EITHER, IF IT IS NOT AVAILABLE WHEN AND WHERE THEY NEED IT.**

**ONLY 27 PER CENT OF PEOPLE WITH DEMENTIA APPROVED FOR RESPITE RESIDENTIAL CARE USE IT WITHIN A YEAR OF THEIR APPROVAL. THE REASONS FOR THE UNDERUSE OF RESPITE ARE COMPLEX. IMPORTANT CONTRIBUTORY FACTORS ARE THAT RESPITE CARE IS INFLEXIBLE, NOT AVAILABLE AT THE RIGHT TIME OR IT PROVIDES INSUFFICIENT HOURS OF CARE.**

**SOMETIMES CARERS ARE RELUCTANT TO USE A SERVICE BECAUSE THERE IS NO PERCEIVED BENEFIT FOR THE PERSON WITH DEMENTIA.**



**SOMETIMES SERVICE PROVIDERS FEEL UNABLE TO PROVIDE AND APPROPRIATELY SUPPORT INDIVIDUALS WITH BEHAVIOURAL AND PSYCHOLOGICAL SYMPTOMS OF DEMENTIA. FAMILY CARERS REPORT THAT ONCE THE PERSON WITH DEMENTIA DEVELOPS THESE SYMPTOMS SOME SERVICE PROVIDERS REFUSE TO CONTINUE PROVIDING SUPPORT.**

**AND SOMETIMES A CARER FEELS GUILTY AT THE VERY THOUGHT OF RESPITE CARE AND YET RESPITE CARE IS AN IMPORTANT NECESSITY OF THE DEMENTIA JOURNEY.**

**WE HAVE PROPOSED THAT THE GOVERNMENT SHOULD TRIAL THE CASHING OUT OF THE VALUE OF RESPITE TO THE FAMILY CARER SO THE CARER CAN DECIDE HOW THE MONEY IS SPENT.**

**WE BELIEVE THIS MODEL COULD BE PARTICULARLY USEFUL IN DIVERSE COMMUNITIES AS WELL AS IN RURAL AND REMOTE AREAS TO INCREASE THE FLEXIBILITY OF THE FUNDING AVAILABLE.**

**WE RECOGNISE THAT THE CASHING OUT OF THE VALUE OF SERVICES IN THIS WAY IS COMPLEX AND THAT THERE ARE MANY DIFFICULT QUESTIONS TO ANSWER INCLUDING WHETHER BETTER QUALITY CARE WOULD RESULT, WHETHER IT WOULD BE SUBJECT TO ABUSE, AS WELL AS WORKFORCE ISSUES.**

**IT IS INEVITABLE THAT SOME PEOPLE WILL NEED ACCESS TO RESIDENTIAL CARE. IT IS IMPERATIVE THAT WE HAVE A HIGH QUALITY RESIDENTIAL CARE SYSTEM THAT RESPECTS THE RIGHTS OF RESIDENTS.**

**I DON'T BELIEVE THAT TO BE THE CASE NOW.**

**SOME FACILITIES PROVIDE EXCELLENT CARE BUT IT SEEMS TO ME THAT THE MAJORITY STRUGGLE TO APPROPRIATELY CARE FOR PEOPLE WITH HIGH CARE NEEDS.**

**THERE IS NO DOUBT ON THE BASIS OF THE CONSULTATIONS ALZHEIMER'S AUSTRALIA DID FOR THE FORMER MENTAL HEALTH AND AGEING HEALTH MINISTER, MARK BUTLER, (RELEASED LAST YEAR) THAT THE SYSTEM IS OVERWHELMINGLY FAILING OLDER AUSTRALIAN AND PEOPLE WITH DEMENTIA IN ACCESS TO COMMUNITY CARE, QUALITY OF RESIDENTIAL CARE AND THE NEED FOR MORE RESPITE.**

**THERE IS NO TRANSPARENCY IN THE QUALITY OF CARE – THE STANDARDS AND ACCREDITATION AGENCY CHECK SYSTEMS AND RECORDS, RATHER THAN MONITORING OUTCOMES.**

**IT IS INCOMPREHENSIBLE HOW IT IS THAT SOME PROVIDERS EMPLOY LITTLE OR NO RESTRAINTS AND GET GOOD REPORTS FROM CONSUMERS WHILE OTHERS EXHIBIT THE TERRIBLE OUTCOMES WE HAVE SEEN ON FIVE DOCUMENTARIES IN 12 MONTHS ON THE ABC'S LATELINE PROGRAM. ONE WAS SHOWN THIS WEEK.**

**IT REINFORCED THE POOR PAIN MANAGEMENT AND LACK OF PALLIATIVE CARE IN SOME AGED CARE FACILITIES.**

**IT'S NOT JUST A QUESTION OF FUNDS AND TRAINING BUT AN INSTITUTIONAL CULTURE AMONG SOME PROVIDERS THAT INSTILLS IN MANY RESIDENTS AND CARERS A FEAR OF RETRIBUTION – NO COMPLAINTS SYSTEM CAN COMBAT THAT. SOME NURSING HOMES ARE FAR FROM BEING HOMES...**

**THE NEWLY-APPOINTED MINISTER FOR MENTAL HEALTH AND AGEING, SENATOR JACINTA COLLINS, APPEARED ON LATELINE THIS WEEK AND SAID THE GOVERNMENT IS WORKING ON A 10-YEAR PLAN.**

**AUSTRALIA'S ELDERLY CITIZENS AND PEOPLE WITH DEMENTIA WHO ARE RECEIVING LESS THAN ADEQUATE CARE – I HESITATE TO USE THE WORD CARE – CAN'T WAIT 10 YEARS FOR A PLAN. THEY NEED ACTION NOW.**

**ALZHEIMER'S AUSTRALIA'S CONSUMERS TELL US THAT WITHIN WEEKS OF ENTERING RESIDENTIAL CARE, MANY CARERS FIND THAT FAMILY MEMBERS AND FRIENDS THEY'VE SPENT YEARS CARING FOR HAVE BECOME UNRECOGNISABLE IN TERMS OF THEIR PHYSICAL, MENTAL AND EMOTIONAL WELFARE.**

**NEARLY ONE QUARTER OF RESIDENTS ARE CHEMICALLY RESTRAINED WITH ANTI-PSYCHOTIC MEDICATIONS OFTEN WITHOUT THEIR CONSENT, OR THE CONSENT THAT'S LEGALLY REQUIRED FROM THEIR FAMILY.**

**IT IS UNACCEPTABLE THAT SUCH PRACTICES ARE TAKING PLACE TODAY IN AUSTRALIA.**

**THESE MEDICATIONS PROVIDE A CLINICAL BENEFIT TO ONLY 1 IN 5, AND ARE ASSOCIATED WITH AN INCREASED RISK OF SERIOUS SIDE-EFFECTS SUCH AS INCREASED COGNITIVE IMPAIRMENT, INCREASED RISK OF FALLS, STROKES AND DEATH.**

**I HAVE RECEIVED MANY LETTERS AND EMAILS FROM PEOPLE ALL OVER AUSTRALIA ON THIS ISSUE... TELLING STORIES OF FAMILY MEMBERS BEING DENIED ACCESS TO A PERSON WITH DEMENTIA; OF RESIDENTS WITH DEMENTIA BEING GIVEN ANTIPSYCHOTIC DRUGS TO STOP THEM WANDERING AROUND THE BUILDING...**

**“THEY WANTED HIM TO BE ASLEEP IN FRONT OF THE TELEVISION FROM MORNING TO NIGHT,” ONE WOMAN EMAILED ME. “I DIDN’T GIVE PERMISSION FOR DRUGS TO BE ADMINISTERED – FOUR OF THEM,” ANOTHER WOMAN WROTE, “I ONLY DISCOVERED WHAT WAS HAPPENING WHEN I RECEIVED THE BILL FROM THE PHARMACY.”**

**THERE IS LONG-STANDING DISQUIET ABOUT THE QUALITY OF RESIDENTIAL CARE, PARTICULARLY FOR THOSE WITH THE SEVERE BEHAVIOURAL AND PSYCHOLOGICAL SYMPTOMS OF DEMENTIA. WE CANNOT SWEEP THESE CONCERNS UNDER THE CARPET.**

**WHAT IS ALZHEIMER’S AUSTRALIA DOING ABOUT THIS? WE WILL CONTINUE TO RAISE OUR CONCERNS AT EVERY OPPORTUNITY...AND I INTEND TO DO SOMETHING THAT IS SECOND NATURE TO ME...PUBLISH AND BE DAMMED.**

**I AM GATHERING UP ALL MY LETTERS AND EMAILS...AND WITH THE PERMISSION OF THE WRITERS WILL PUT THEM ON THE ALZHEIMER’S AUSTRALIA WEBSITE; WE ARE ALSO GOING TO ASK OUR CONSUMERS TO WRITE TO US WITH THEIR STORIES OF LESS THAN ADEQUATE CARE IF WE HAVE TO SHAME GOVERNMENTS INTO ACTION THEN THAT IS WHAT WE WILL DO.**

**AT THE SAME TIME HOWEVER WE WILL NOT BE DISTRACTED FROM  
ADVOCATING FOR GREATER INVESTMENT IN RESEARCH**

**UNLESS WE CAN IMPROVE OUR UNDERSTANDING OF THE CAUSES OF  
DEMENTIA AND DEVELOP NEW WAYS TO PREVENT, DELAY OR EVEN CURE  
THE DISEASE, WE ARE FACED WITH THE PROSPECT OF HUNDREDS OF  
THOUSANDS OF AUSTRALIANS DEVELOPING DEMENTIA DURING THE NEXT  
37 YEARS.**

**THAT WILL ALMOST CERTAINLY INCLUDE SOME OF US IN THIS ROOM, SO  
WE ALL HAVE A VESTED INTEREST IN DOING WHAT WE CAN TO SUPPORT  
OUR RESEARCHERS – OUTSTANDING RESEARCHERS LIKE RALPH  
MARTINS AND HIS TEAM – IN THEIR FIGHT AGAINST DEMENTIA.**

**AUSTRALIAN DEMENTIA RESEARCH IS UNDERFUNDED IN COMPARISON TO  
RESEARCH ON COMPARABLE CHRONIC DISEASES.**

**IT'S DIFFICULT TO FATHOM GIVEN THAT DEMENTIA IS THE ONLY MAJOR  
CHRONIC DISEASE FOR WHICH WE DO NOT YET HAVE ANY EFFECTIVE  
TREATMENTS.**

**IN THE 2012-13 FINANCIAL YEAR, DEMENTIA RESEARCHERS WERE EXPECTED TO RECEIVE 21.5 MILLION DOLLARS IN RESEARCH FUNDING THROUGH THE NHMRC. IN THE SAME PERIOD, 162.4 MILLION WILL GO TO CANCER RESEARCH, 93.6 MILLION TO CARDIOVASCULAR DISEASE, 63 MILLION TO DIABETES AND 55.1 MILLION TO MENTAL HEALTH RESEARCH.**

**IN RECENT TIMES THIS FIGURE HAS INCREASED WITH AN ANNOUNCEMENT BY THE FEDERAL MINISTER FOR HEALTH LAST MONTH OF SIX NEW DEMENTIA RESEARCH GRANTS WORTH \$3 MILLION.**

**AND EARLIER THIS YEAR MARK BUTLER ANNOUNCED FUNDING OVER FIVE YEARS OF 25 MILLION DOLLARS FOR THE NEW PARTNERSHIP CENTRE ON COGNITIVE DECLINE. ALZHEIMER'S AUSTRALIA IS ONE OF FOUR INDUSTRY PARTNERS IN THE CENTRE.**

**THE LOW LEVEL OF TOTAL FUNDING HAS NOTHING TO DO WITH THE QUALITY OF THE AUSTRALIAN DEMENTIA RESEARCHERS WE HAVE. TO THE CONTRARY OUR DEMENTIA RESEACHERS ARE AS SUCCESSFUL IN THEIR FUNDING APPLICATIONS AS RESEARCHERS FROM OTHER FIELDS.**

**THE PROBLEM IS THAT THERE ARE SIMPLY NOT ENOUGH RESEARCHERS WORKING ON THE CHALLENGES OF ALZHEIMER'S DISEASE AND OTHER DEMENTIAS. IN PARTICULAR, THERE ARE NOT ENOUGH STUDENTS AND EARLY CAREER RESEARCHERS STARTING THEIR CAREERS AS PART OF THE GLOBAL RESEARCH EFFORT TO BEAT DEMENTIA.**

**WE NEED TO BUILD CAPACITY IN DEMENTIA RESEARCH**

**OTHER COUNTRIES ARE SHOWING THE WAY. LAST YEAR, PRESIDENT OBAMA ENDORSED A PLAN TO DEVELOP EFFECTIVE APPROACHES TO PREVENTING AND TREATING DEMENTIA BY 2025, PROVIDING AN IMMEDIATE INJECTION OF \$100 MILLION FOR DEMENTIA RESEARCH.**

**THE THIRD FRENCH NATIONAL DEMENTIA PLAN INCLUDED A COMMITMENT OF 2.3 BILLION DOLLARS FOR NEW SERVICES AND RESEARCH, AND THIS YEAR THE BRITISH PRIME MINISTER DAVID CAMERON COMMITTED TO DOUBLING INVESTMENT IN DEMENTIA RESEARCH BY 2015.**

**UNLESS WE PLAY OUR PART IN THE INTERNATIONAL EFFORT IT IS LIKELY THAT AUSTRALIANS WILL EXPERIENCE DELAYS IN GETTING ACCESS TO NEW TREATMENTS AND BETTER MODELS OF CARE.**

**THE BASIS FOR DOING BETTER IN AUSTRALIA HAS BEEN LAID BY THE MCKEON REVIEW OF HEALTH AND MEDICAL RESEARCH THAT WAS TABLED IN PARLIAMENT EARLIER THIS YEAR.**

**WE ARE YET TO SEE THE GOVERNMENT'S RESPONSE TO THE REVIEW, BUT WE WERE PLEASED TO SEE IT INCLUDED RECOMMENDATIONS TO INCREASE FUNDING FOR RESEARCH ON NATIONAL HEALTH PRIORITY AREAS SUCH AS DEMENTIA, TO BETTER TARGET FUNDING TO ENSURE TRANSLATION OF RESEARCH FINDINGS, AND A RECOMMENDATION TO FACILITATE CONSUMER ENGAGEMENT IN THE RESEARCH PROCESS.**



**IN OUR ELECTION CAMPAIGN DOCUMENT WE ARE SEEKING \$200 MILLION OVER FIVE YEARS. IF AUSTRALIANS ARE TO HAVE CONFIDENCE IN BEATING THIS TERRIBLE DISEASE THIS KIND OF SIGNIFICANT INVESTMENT IS CRUCIAL.**

- **WE NEED TO GET NEW RESEARCHERS INTO THE FIELD. SPECIFICALLY, ALZHEIMER'S AUSTRALIA IS CALLING ON THE GOVERNMENT TO SUPPORT 150 NEW DEMENTIA RESEARCHERS WITH A RANGE OF POSTGRADUATE SCHOLARSHIPS AND EARLY AND MID-CAREER FELLOWSHIPS OVER THE NEXT 5 YEARS THROUGH BOTH THE NHMRC AND THE AUSTRALIAN RESEARCH COUNCIL.**
- **WE NEED TO DO MORE TO SUPPORT DEMENTIA RESEARCH IN THE PRIORITY AREAS IDENTIFIED BY POLICY MAKERS, SERVICE PROVIDERS AND CONSUMERS. INCREASED ATTENTION TO PRIORITY DRIVEN RESEARCH WAS A CENTRAL THEME OF THE MCKEON REVIEW.**
- **WE NEED TO COMMIT SUFFICIENT RESOURCES TO ENSURE THAT THE NEW KNOWLEDGE PRODUCED BY OUR RESEARCHERS FINDS ITS WAY INTO THE HEALTH AND AGED CARE SERVICES THAT HAVE A MAJOR IMPACT ON THE QUALITY OF LIFE OF PEOPLE WITH DEMENTIA AND THOSE WHO PROVIDE THEM WITH SUPPORT AND CARE.**

- **WE NEED TO INVEST IN THE EQUIPMENT AND INFRASTRUCTURE THAT WILL LET OUR RESEARCHERS DO THEIR JOB. FOR EXAMPLE, THERE ARE ONLY TWO RESEARCH FACILITIES IN AUSTRALIA, ONE OF THEM RIGHT HERE IN PERTH, THAT HAVE THE CAPACITY TO PERFORM THE SPECIALISED PET BRAIN SCANS REQUIRED TO DETECT THE VERY EARLIEST STAGES OF ALZHEIMER'S DISEASE.**

**THE COMMITMENT WE ARE SEEKING FROM GOVERNMENT OF 200 MILLION DOLLARS OVER FIVE YEARS IS A SMALL INVESTMENT IN THE CONTEXT OF GOVERNMENT RESEARCH FUNDING AND THE FIVE BILLION ANNUAL HEALTH COST OF DEMENTIA.**

**THERE IS NO EXCUSE FOR INACTION AS WE KNOW – AND SO DO ALL THE POLITICANS OF THE MAJOR AND MINOR PARTIES ACROSS THE NATION – THAT THE NUMBERS OF PEOPLE WITH DEMENTIA WILL ONLY INCREASE.**

**WE NEED VISIONARY LEADERSHIP TO TACKLE DEMENTIA AND I CALL ON BOTH SIDES OF POLITICS TO RESPOND TO OUR FIGHT DEMENTIA CAMPAIGN DOCUMENT.**

**I ALSO ASK ALL OF YOU TO SUPPORT OUR FIGHT DEMENTIA CAMPAIGN DOCUMENT... HELP US AND PEOPLE WITH DEMENTIA AND THEIR FAMILY CARERS, TAKE THE BATTLE TO THOSE STANDING AT THE FEDERAL ELECTION. THANK YOU.**