

The Future of Seniors

THE FUTURE OF SENIORS IN AUSTRALIA

**AGED AND COMMUNITIES SERVICES AUSTRALIA (ACSA) CONFERENCE
MELBOURNE CONVENTION & EXHIBITION CENTRE**

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I AM DELIGHTED TO HAVE THE OPPORTUNITY TO SPEAK AT THIS CONFERENCE WITH ITS PROVOCATIVE THEME: FACING REFORM: JUMPING HURDLES AND STAYING IN THE RACE.

KEEPING THE THEME IN MIND I HAVE BEEN ASKED TO ADDRESS THE FUTURE OF SENIORS IN AUSTRALIA – WELL, LET ME TELL YOU, THERE ARE TIMES WHEN I FEEL IT’S SOMEWHAT BLEAK.

AS AN OLDER AUSTRALIAN AND A PERSON WHO HAS BEEN INVOLVED IN THE AGED CARE SECTOR FOR A NUMBER OF YEARS NOW, I’M NOT HAPPY THAT I THINK THAT WAY. THERE IS MUCH TO BE DONE.

SURVEY AFTER SURVEY TELLS US THAT QUALITY CARE IN THEIR LATER YEARS IS A MAJOR CONCERN FOR AUSTRALIANS AS THEY AGE.

THEY WANT – AND EXPECT – AFFORDABLE QUALITY CARE.

FOR THIS TO HAPPEN FOR ALL AUSTRALIANS WHO WILL NEED SUCH CARE, THERE WILL NEED TO BE A SIGNIFICANT INVESTMENT IN AGED CARE WHICH MUST INCLUDE DEVELOPING A BIGGER, AND WELL-TRAINED WORKFORCE TO DELIVER THE CARE REQUIRED.

QUALITY CARE MUST BE AVAILABLE TO PEOPLE WHO CAN’T AFFORD TO PAY FOR IT WHILE THOSE WHO CAN, WILL NEED TO PAY. AND AGAIN SURVEYS TELL US THAT MANY AUSTRALIANS ARE HAPPY TO DO THIS.

WHEN I BECAME THE AUSTRALIAN OF THE YEAR, I SAID I WOULD USE THIS YEAR TO RAISE AWARENESS OF ISSUES OF CONNER FACING OLDER AUSTRILIANS, SUCH AS TACKLING THE AGEISM THAT EXISTS IN OUR COMMUNITY, ADVOCATING FOR BETTER AGED CARE CHOICES, IMPROVED EMPLOYMENT OPPORTUNITIES AND BETTER RESPECT. AND AS PRESIDENT OF ALZHEIMER'S AUSTRALIA TO RAISE AWARENESS OF DEMENTIA AND DO I COULD TO REMOVE THE STIGMA AND SENSE OF SHAME THAT COMES WITH A DIAGNOSIS OF DEMENTIA.

BEING AUSTRALIAN OF THE YEAR IS A HUGE HONOUR AND SOMETHING YOU NEVER IMAGINE HAPPENING TO YOU. IT PROVIDES A WIDER PLATFORM AND AN AUTHORITY TO SAY WHAT'S ON MY MIND ABOUT ISSUES I'M PASSIONATE ABOUT. I TRY NEVER TO WASTE ANY OPPORTUNITY THAT COMES MY WAY, TO DO THIS.

I'M SURE THAT ALL OF US WHO ARE INVOLVED IN THE AGED CARE SECTOR WOULD AGREE THAT IF WE ARE TO STAY IN THE RACE WE ALSO NEED TO DO A GREAT DEAL MORE TO RAISE THE PROFILE OF AGED CARE AS WELL AS THE NECESSITY FOR CONTINUED REFORM.

I BELIEVE THERE'S MUCH TO LEARN FROM THE DISABILITY SECTOR AND ITS COMMITMENT TO REFORM AND INNOVATION.

THE NATIONAL DISABILITIES INSURANCE SCHEME IS AMBITIOUS IN ITS REFORM AGENDA. SURE IT WILL HAVE TO TACKLE SOME CHALLENGING ISSUES BEFORE DELIVERING ON THE PROMISE OF A FUNDED SYSTEM THAT RESPONDS TO THE INDIVIDUAL NEEDS OF PEOPLE WITH DISABILITIES.

BUT THE DISABILITY SECTOR IS GETTING ON WITH THE JOB AS A UNITY. BY CONTRAST THE AGED CARE SECTOR SEEMS TO BE STRUGGLING TO BUILD ON THE SUCCESS OF GETTING AGED CARE REFORM ONTO THE POLITICAL AGENDA IN APRIL 2012.

WE KNOW FROM THE RECENT ELECTION THAT DIVISION IS DEATH AND WE SHOULDN'T FORGET THAT NEITHER LEADER COULD QUITE RECALL DURING THE FIRST PRE-ELECTION DEBATE WHAT AGED CARE REFORM WAS ALL ABOUT.

FOR CONSUMERS THE AGED CARE REFORM PROCESS HOLDS OUT THE PROMISE OF MORE CHOICE, GREATER QUALITY AND SUSTAINABLE FUNDING FOR AGED CARE AND, I HOPE, SIMPLIFIED ADMINISTRATION AND PROGRAM STRUCTURES.

ALZHEIMER'S AUSTRALIA HAS WELCOMED THE EXPANSION IN COMMUNITY CARE, THE INTRODUCTION OF CONSUMER-DIRECTED CARE AND THE FOCUS ON IMPROVING THE QUALITY OF CARE.

WE'RE ENCOURAGED AT THE PROSPECT OF THE INCREASE OF COMMUNITY CARE PLACES FROM 64,800 TO 144,469 IN THE NEXT 10 YEARS.

BUT LIKE OTHER STAKEHOLDERS WE DO HAVE CONCERNS ABOUT THE REFORMS. FOR EXAMPLE, WE KNOW THAT MOVING AWAY FROM THE DIVISION OF HIGH CARE AND LOW CARE, AND THE IMPLEMENTATION OF CHANGED USER CHARGING SYSTEMS IN COMMUNITY AND RESIDENTIAL CARE WILL PRESENT CONSUMERS WITH SOME DIFFICULT ISSUES.

WE ACKNOWLEDGE THAT REFORMS DO COME AT A COST BUT THE QUID PRO QUO IS HIGHER QUALITY OF CARE AND GREATER CHOICE.

THE MODEL OF CONSUMER- DIRECTED CARE BEING ADOPTED IN THE AGED CARE SECTOR PROVIDES AN IMPORTANT SHIFT IN THE PHILOSOPHY OF CARE. IT'S A MODEL FOR WHICH ALZHEIMER'S AUSTRALIA HAS BEEN ADVOCATING FOR MORE THAN A DECADE AND PRESENTS CONSUMERS WITH THE POSSIBILITY OF KNOWING WHAT RESOURCES ARE AVAILABLE TO THEM FOR THEIR CARE NEEDS AS WELL AS TRANSPARENCY AROUND HOW THESE RESOURCES ARE USED.

IT ALSO ESTABLISHES A BASIS FOR A PARTNERSHIP BETWEEN CONSUMERS AND PROVIDERS, AND GIVES VALIDITY TO THE LONG TERM COMMITMENT OF ALL OF US TO PERSON-CENTRED CARE.

AS PARTNERS THE REALITY IS THAT PERSON-CENTRED CARE MIGHT BE MORE ACHEIVABLE BECAUSE THERE WILL BE A CLEARER UNDERSTANDING OF WHAT THE INDIVIDUAL NEEDS ARE OF THE PERSON WHO REQUIRES CARE AND SUPPORT.

MOST CONSUMERS SUPPORT THE BUDGET HOLDING MODEL IT'S ATTRACTIVE BECAUSE IT ENABLES THEM TO KNOW WHAT FUNDS ARE AVAILABLE FOR CARE AND TO HAVE A SAY IN HOW IT IS MANAGED.

I'M PRETTY SURE THE MAJORITY OF OLDER PEOPLE DON'T WANT TO BE EMPLOYERS OR HOLD THE CASH AND THEREFORE WILL REQUIRE SOME ASSISTANCE IN DEVELOPING THEIR CARE PLANS.

THE CDC MODEL BEING ADOPTED IN AGED CARE WHILE QUITE DIFFERENT FROM THE DISABILITY SECTOR'S INDIVIDUALISED FUNDING MODEL NONETHELESS REPRESENTS A HUGE CULTURAL SHIFT IN THE RELATIONSHIP BETWEEN CONSUMERS, SERVICE PROVIDERS AND THEIR STAFF.

ALZHEIMER'S AUSTRALIA WOULD ALSO LIKE TO SEE A MORE AMBITIOUS APPROACH IN THE AREA OF INDIVIDUALISED FUNDING. IN THE LAST THREE YEARS WE'VE ADVOCATED FOR A TRIAL TO TEST THE CONCEPT OF INDIVIDUALISED FUNDING IN RESPITE CARE... FOR THREE REASONS.

- **RESPITE CARE IS THE SERVICE TO WHICH PEOPLE WITH DEMENTIA AND THEIR CARERS ATTACH A HIGH PRIORITY – IN FACT HIGHER THAN ANY OTHER FAMILY CARERS.**
- **RESPITE CARE IS OFTEN DIFFICULT TO ACCESS FOR THOSE WITH MODERATE OR LATER STAGE DEMENTIA.**
- **CONSUMERS' NEEDS ARE HUGELY VARIABLE IN TERMS OF HOW, WHEN AND WHERE RESPITE CARE IS NEEDED OR WHETHER IT IS PLANNED OR EMERGENCY AND OF COURSE, FOR RESPITE TO BE SUCCESSFUL IT NEEDS TO PROVIDE SOCIAL ENGAGEMENT FOR THE PERSON WITH DEMENTIA.**

FLEXIBILITY IN SERVICE DELIVERY IS PARAMOUNT. IT MAY BE POSSIBLE TO LEARN THROUGH A TRIAL MUCH ABOUT CONSUMER NEEDS, THE QUALITY OF SERVICE THAT WOULD RESULT, SAFETY ISSUES AND ACCOUNTABILITY.

ALZHEIMER'S AUSTRALIA REMAINS COMMITTED TO THE REFORM PROCESS AND WE HAVE CONSISTENTLY TAKEN THE VIEW THAT THE AGED CARE REFORM PROCESS WOULD TAKE 10 YEARS TO IMPLEMENT BUT A TRULY NATIONAL AGED CARE PROGRAM IS WORTH THE WAIT.

I BELIEVE THAT THE MAJORITY OF AGED CARE SERVICE PROVIDERS AND STAFF WILL WELCOME THE OPPORTUNITY TO PUT TOGETHER PLANS AND SERVICES THAT BETTER RESPOND TO THE NEEDS OF OLDER PEOPLE BECAUSE THAT'S WHAT THEY'RE COMMITTED TO DOING.

ALL OF US HERE TODAY WANT TO ACHIEVE IMPROVED CARE OUTCOMES. TO MEET THE CHALLENGE THAT AIM REPRESENTS WE NEED A RENEWED COMMITMENT BETWEEN SERVICE PROVIDERS, UNIONS, PROFESSIONAL BODIES AND CONSUMER ORGANISATIONS TO CONFRONT ISSUES THAT FOR TOO LONG HAVE BEEN SLEEPERS IN AGED CARE.

I'D NOW LIKE TO SPEND SOME TIME NOW LOOKING AT THREE OF THOSE ISSUES.

- **PATHWAYS AND INTEGRATED APPROACHES TO AGED CARE**
- **QUALITY OF CARE**
- **MAKING AUSTRALIA DEMENTIA FRIENDLY.**

WE CANNOT ADDRESS THE FUTURE OF SENIORS IN AUSTRALIA WITHOUT ADDRESSING THE ISSUE OF DEMENTIA.

DEMENTIA IS THE SECOND MOST FEARED DISEASE NEXT TO CANCER, AND THE MOST FEARED AMONG OLDER AUSTRALIANS. SIXTY PER CENT OF ADULT AUSTRALIANS EITHER HAVE A PERSON IN THEIR OWN FAMILY WITH DEMENTIA OR KNOW SOMEONE WHO HAS THE DISEASE.

1700 NEW CASES ARE DIAGNOSED EVERY WEEK; ABOUT 60 PER CENT OF AGED CARE FACILITY BEDS ARE OCCUPIED BY SOMEONE WITH DEMENTIA.

PEOPLE WITH DEMENTIA OFTEN REQUIRE SPECIALISED CARE, NOT ONLY IN RESIDENTIAL CARE, BUT ALSO IN THE COMMUNITY AND IN RESPITE SERVICES.

LIVING LONGER, LIVING BETTER PROVIDES FOR AN INCREASE IN RESIDENTIAL PLACES FROM 188,000 IN 2012 TO ALMOST 257,000 BY 2021. THAT'S A GROWTH OF 37 PER CENT IN RESIDENTIAL CARE OVER 10 YEARS; UP FROM 22 PER CENT OVER THE PREVIOUS DECADE.

IN THE COMMUNITY, GROWTH WILL BE EVEN FASTER, INCREASING 129 PER CENT FROM 61,000 PACKAGES IN 2012 TO 139,500 BY 2021.

EXPANSION OF THIS MAGNITUDE WILL REQUIRE ENORMOUS FINANCIAL INVESTMENT, AS WELL AS INVESTMENT IN THE SKILLS OF THE WORKFORCE.

BUT IT'S A CHALLENGE CONSUMERS ARE LOOKING TO THE AGED CARE SECTOR TO MEET.

WE WILL NEED MORE THAN JUST ADDITIONAL CARE PLACES. IT'S ESTIMATED THAT 10 PER CENT OF PEOPLE WITH DEMENTIA WILL EXPERIENCE SEVERE OR EXTREME BEHAVIOURAL AND PSYCHOLOGICAL SYMPTOMS. RIGHT NOW AROUND 32,000 PEOPLE IN AUSTRALIA REQUIRE DEMENTIA SPECIFIC NURSING HOMES OR SPECIALIST PSYCHOGERIATRIC CARE.

ACCESS TO THIS TYPE OF SPECIALISED CARE IS LIMITED AND MANY PEOPLE STRUGGLE TO GET ACCESS TO APPROPRIATE CARE.

SO TODAY I WANT TO TAKE THE OPPORTUNITY THIS CONFERENCE PROVIDES TO LAUNCH A LANDMARK REPORT, *COLLABORATING FOR A BETTER FUTURE FOR AUSTRALIANS WITH ALZHEIMER'S DISEASE* WHICH PROVIDES RECOMMENDATIONS ON A WAY FORWARD FOR DEVELOPING A MORE SEAMLESS INTEGRATED SYSTEM OF CARE.

AT OUR NATIONAL ALZHEIMER'S AUSTRALIA CONFERENCE EARLIER THIS YEAR, WITH SUPPORT FROM ELI LILLY, WE BROUGHT TOGETHER A GROUP OF EXPERTS AT A ROUND TABLE THAT INCLUDED CLINICIANS, RESEARCHERS, CONSUMERS AND NURSES TO DEVELOP A ROADMAP FOR CHANGE TO IMPROVE THE DIAGNOSIS, CARE AND SUPPORT FOR PEOPLE WITH DEMENTIA.

PEOPLE WITH DEMENTIA OFTEN TELL US THAT AFTER FIRST NOTICING SOMETHING IS WRONG GETTING ACCESS TO CARE AND SUPPORT IS NOT EASY.

IT OFTEN STARTS WITH TRYING TO GET A DIAGNOSIS. USUALLY A VISIT TO THE GP IS THE FIRST PORT OF CALL AFTER NOTICING MEMORY PROBLEMS; HOWEVER ON AVERAGE PEOPLE WAIT 3.1 YEARS BETWEEN FIRST NOTICING SYMPTOMS OF DEMENTIA AND FINALLY GETTING A DIAGNOSIS. FOR PEOPLE FROM CULTURALLY AND LINGUISTICALLY DIVERSE BACKGROUNDS THIS DELAY CAN BE EVEN LONGER.

ONCE A DIAGNOSIS IS MADE, PEOPLE ARE OFTEN LEFT UNSURE AS TO WHERE TO TURN TO NEXT. FEW ARE REFERRED TO THE SERVICES OF ALZHEIMER'S AUSTRALIA OR OTHER COMMUNITY SUPPORT SERVICES EARLY IN THE DISEASE. INSTEAD THEY ARE LEFT TO FIND THEIR WAY ON THEIR OWN.

SEVENTY PER CENT OF PEOPLE WITH DEMENTIA ARE LIVING IN THE COMMUNITY, A FACT THAT'S OFTEN OVERLOOKED, AND MANY OF THEM ARE NOT ACCESSING ANY SERVICES.

DATA FROM THE AUSTRALIAN INSTITUTE OF HEALTH AND WELFARE SUGGESTS THAT 22 PER CENT OF PEOPLE LIVING WITH DEMENTIA IN THE COMMUNITY ARE NOT ACCESSING ANY FORMAL SERVICES.

AND WE KNOW THE JOURNEY WITH DEMENTIA, ALTHOUGH ALWAYS A TOUGH ONE, CAN BE SO DIFFERENT FOR PEOPLE WHO GET A TIMELY DIAGNOSIS AND ACCESS CARE AND SUPPORT COMPARED TO PEOPLE WHO STRUGGLE FOR YEARS TO GET A DIAGNOSIS.

KEY RECOMMENDATIONS FROM OUR REPORT INCLUDE:

- **THE ADOPTION OF A NATIONAL BEST-PRACTICE, MULTIDISCIPLINARY APPROACH FOR THE DIAGNOSIS, TREATMENT AND CARE OF DEMENTIA AND ALZHEIMER'S DISEASE IN AUSTRALIA.**

- **A CRITICAL NEED TO BUILD A DEMENTIA WORKFORCE TO MEET THE GROWING NEED FOR SPECIALISED CARE**
- **FUNDING OF A NATIONAL PROGRAM OF KEY WORKERS FOR PEOPLE WITH DEMENTIA THAT PROVIDE ONE-ON-ONE SUPPORT FROM THE POINT OF DIAGNOSIS ONWARDS.**
- **GREATER ONGOING INVESTMENT IN DEMENTIA RESEARCH.**
- **DESTIGMATISATION OF DEMENTIA AND A RECOGNITION THAT THE EXPERIENCE OF DEMENTIA IS UNIQUE TO EACH PERSON.**

CLEARLY THERE IS NO SINGLE MODEL OF CARE THAT WILL SUIT EVERYONE WHICH IS WHY A PERSON-CENTRED APPROACH TO CARE IS CRITICAL WITH THE AIM OF CREATING A MORE SEAMLESS SYSTEM OF SUPPORT WHERE CONNECTIONS ARE MADE BETWEEN GPs, COMMUNITY SUPPORT, HOSPITALS AND THE AGED CARE SYSTEM.

THE FIRST STEP IN ACHIEVING THIS SYSTEM MUST BE THE DEVELOPMENT OF A NEW NATIONAL FRAMEWORK FOR ACTION ON DEMENTIA. THE CURRENT FRAMEWORK TERMINATED IN 2010 AND HAS SINCE BEEN RENEWED SINCE WITHOUT REVISION PENDING DECISIONS ON THE AGED CARE REFORMS.

THERE ALREADY HAS BEEN SOME WORK DONE IN DRAFTING A NEW FRAMEWORK. THERE IS NOW SOME URGENCY IN GETTING THE AGREEMENT OF HEALTH MINISTERS TO DEVELOP A NEW FRAMEWORK TO PROVIDE A BASIS OF THE WORK THAT'S REQUIRED TO SUPPORT THE HEALTH MINISTERS' COMMITMENT TO DEMENTIA AS A NATIONAL HEALTH PRIORITY AREA.

WE ALL KNOW THAT FUNDING IS TIGHT – THAT'S PROBABLY THE UNDERSTATEMENT OF THE YEAR. BUT SURELY WE CAN SET SOME ASPIRATIONAL GOALS THAT WILL GUIDE THE WORK OF GOVERNMENTS.

FOR EXAMPLE, OVER THE LIFE OF THE NEXT AGREEMENT, COULD WE AIM TO ENSURE THAT:

- **85 PER CENT OF AUSTRALIANS WILL UNDERSTAND THE DIFFERENCE BETWEEN THE SYMPTOMS OF NORMAL AGEING AND DEMENTIA.**
- **80 PER CENT OF AUSTRALIANS WILL UNDERSTAND THE POTENTIAL FOR DEMENTIA RISK REDUCTION**
- **75 PER CENT OF GPs, NURSE PRACTITIONERS AND PRACTICE NURSES WILL HAVE RECEIVED DEMENTIA TRAINING IN AN EFFORT TO ACHIEVE TIMELY DIAGNOSIS**
- **90 PER CENT OF HOSPITALS WILL HAVE STRATEGIES IN PLACE TO SCREEN AND APPROPRIATELY IDENTIFY INDIVIDUALS WITH COGNITIVE IMPAIRMENT**

WE DON'T WANT TO SET OURSELVES UP FOR FAILURE BUT UNLESS WE HAVE ASPIRATIONS THERE WILL BE NO PROGRESS IN OUR LONG-TERM GOAL OF MOVING TOWARDS A WORLD WITHOUT DEMENTIA.

MAKING SURE DEMENTIA IS ON THE AGENDA OF AUSTRALIA'S HEALTH MINISTERS IS EVEN MORE IMPORTANT NOW THAT THE DEPARTMENT OF SOCIAL SERVICES HAS RESPONSIBILITY FOR AGED CARE.

WE NEED TO ENSURE THAT STATES AND TERRITORIES AND THE FEDERAL GOVERNMENT ARE WORKING TOGETHER TO ENABLE PEOPLE WITH DEMENTIA TO HAVE ACCESS TO APPROPRIATE CARE ACROSS BOTH THE HEALTH AND AGED CARE SYSTEMS.

WE ALSO NEED TO RECOGNISE THE IMPORTANCE OF ONE-ON-ONE SUPPORT TO ASSIST PEOPLE WITH DEMENTIA IN NAVIGATING THE SERVICE SYSTEM, SO THAT NO ONE FALLS THROUGH THE GAPS IN THE SYSTEM.

IN CANADA, THE ALZHEIMER'S SOCIETY RUNS A PROGRAM CALLED 'FIRST LINK'. WHEN A PERSON IS DIAGNOSED WITH DEMENTIA, THEIR GP ASKS THEM IF THEY ARE WILLING TO LET THEIR INFORMATION BE SHARED WITH THE LOCAL ALZHEIMER'S ORGANISATION.

IF THE PERSON AGREES, THIS INFORMATION IS THEN PASSED ON TO THE ORGANISATION WHO CONTACTS THE PERSON DIRECTLY.

THIS APPROACH HAS LED TO A DECREASE IN AVERAGE REFERRAL TIME TO SERVICES AFTER DIAGNOSIS FROM 18 MONTHS TO 7 MONTHS.

BECAUSE 'FIRST LINK' FOCUSES ON SERVICE COORDINATION, RESOURCES AND PLANNING, PEOPLE BECOME MORE CONFIDENT AND INVOLVED IN THEIR OWN CARE, REDUCING THE BURDEN ON THE HEALTH SYSTEM AND EMPOWERING THE CONSUMER. FAMILIES ARE BETTER EQUIPPED TO CREATE THEIR OWN PLANS TO TACKLE FUTURE LEGAL, FINANCIAL AND HEALTH NEEDS.

THIS APPROACH IS IMPORTANT AS OFTEN AFTER A DIAGNOSIS, EVEN IF THE DOCTOR HAS GIVEN FAMILY INFORMATION ABOUT THE SERVICES OF ALZHEIMER'S AUSTRALIA, PEOPLE ARE NOT SURE WHAT THE NEXT STEP SHOULD BE. FAMILY CARERS OFTEN THINK THAT THE PERSON IS TOO WELL TO START LOOKING FOR SERVICES AND SUPPORTS – WHICH IS WHY WE NEED TO BE PROACTIVE.

WE ARE TAKING THIS TYPE OF APPROACH IN AUSTRALIA WITH THE YOUNGER ONSET DEMENTIA KEY WORKERS, A SERVICE THAT PROVIDES PEOPLE WITH ASSISTANCE IN NAVIGATING SERVICES AND SUPPORT FROM THE MOMENT OF DIAGNOSIS, THROUGH THE ENTIRE DEMENTIA JOURNEY.

THERE IS A NEED TO CONSIDER HOW THIS CAN BE EXPANDED TO SUPPORT ALL PEOPLE WITH DEMENTIA OF ALL AGES.

FOR PEOPLE WHO ARE FROM THE MOST VULNERABLE GROUPS, SUCH AS THE HOMELESS, PEOPLE WHO LIVE ALONE, THOSE FROM CALD BACKGROUNDS, OR ABORIGINAL AND TORRES STRAIT ISLANDERS, ACCESS TO SERVICES IS EVEN MORE DIFFICULT WHICH MAKES THIS APPROACH EVEN MORE CRUCIAL.

BEING THE KIND OF PERSON WHO LIKES TO MAKE THE MOST OF *ALL* OPPORTUNITIES THAT COME MY WAY....I'M ALSO LAUNCHING ANOTHER REPORT TODAY: *QUALITY OF RESIDENTIAL AGED CARE: THE CONSUMER PERSPECTIVE* WHICH OUTLINES THE NEED FOR ACTION TO ENABLE ALL AUSTRALIANS TO HAVE ACCESS TO QUALITY RESIDENTIAL AGED CARE.

IT WAS WRITTEN BY ALZHEIMER'S AUSTRALIA FOR THE COURAGEOUS PEOPLE WHO HAVE TOLD THE STORIES OF THEIR EXPERIENCES OF RESIDENTIAL CARE – SOME GOOD, BUT MANY OF CONCERN.

IN ADVANCE OF THE ESTABLISHMENT OF THE NEW QUALITY AGENCY ON JANUARY 1, 2014, WE BELIEVE IS IT HELPFUL TO REFOCUS THE AGED CARE REFORM PROCESS ON QUALITY ISSUES.

OUR STARTING POINT IS THAT AUSTRALIA HAS MUCH TO BE PROUD OF IN OUR AGED CARE SYSTEM. INTERNATIONALLY, AUSTRALIA IS RECOGNISED AS HAVING A HIGH QUALITY SYSTEM OF CARE.

SOME VERY DEDICATED PEOPLE WORK WITHIN AGED CARE. THERE IS NEARLY A QUARTER OF A MILLION CARE STAFF WORKING IN THE SECTOR. THEY ARE DEDICATED, COMPASSIONATE PEOPLE WHO WORK HARD EVERY DAY TO PROVIDE THE BEST CARE THEY CAN.

FOR THE MOST PART, THE AGED CARE SECTOR DELIVERS GOOD CARE IN BOTH COMMUNITY AND RESIDENTIAL CARE. MANY PEOPLE BENEFIT FROM BEING IN RESIDENTIAL AGED CARE AND FIND THE OPPORTUNITIES FOR INTERACTION WITH OTHER RESIDENTS AND THE STAFF TO BE BENEFICIAL.

AND OF COURSE, THE SUPPORT PROVIDED THROUGH HOME CARE PACKAGES MEAN THAT MANY PEOPLE ARE ABLE TO STAY IN THE COMMUNITY FOR LONGER.

BUT WHAT WORRIES ME IS A MINORITY OF FACILITIES ARE NOT PROVIDING GOOD CARE, AND THAT RESIDENTS ARE NOT BEING RESPECTED AND, IN SOME CASES, ARE EXPERIENCING PHYSICAL OR PSYCHOLOGICAL ABUSE.

OLDER PEOPLE IN RESIDENTIAL CARE ARE AMONG THE MOST VULNERABLE IN OUR SOCIETY. MANY HAVE COGNITIVE IMPAIRMENT OF SOME KIND, AS WELL AS PHYSICAL DISABILITIES. MANY HAVE LITTLE CONTACT WITH THE OUTSIDE WORLD.

ONLY IN THE RAREST CASES DOES ABUSE HAPPEN AS A RESULT OF INTENTIONAL CRUELTY AND IN AN INDUSTRY CARING FOR MORE THAN 200,000 OLDER PEOPLE EVERY DAY, THERE ARE GOING TO OCCASIONS WHEN CARE FALLS SHORT.

WE ALL WANT TO STRIVE FOR A HIGH QUALITY RESIDENTIAL CARE SYSTEM THAT RESPECTS THE RIGHTS OF RESIDENTS AND I'M SURE WE ALL AGREE THERE SHOULD BE A ZERO TOLERANCE POLICY FOR POOR QUALITY CARE.

THERE ARE ALREADY IMPORTANT PROTECTIONS IN PLACE. AS WE'RE ALL AWARE THE AGED CARE SYSTEM IS ONE OF THE MOST REGULATED INDUSTRIES IN AUSTRALIA.

OVER THE YEARS, THE AGED CARE COMPLAINTS SCHEME AND THE AGED CARE STANDARDS AND ACCREDITATION AGENCY, HAVE ENDEAVOURED TO MAKE SURE THERE ARE PROTECTIONS IN PLACE TO ENSURE QUALITY CARE IS PROVIDED TO RESIDENTS.

BUT FROM THE STORIES I RECEIVE FROM CONSUMERS AND SOMETIMES STAFF, IT SEEMS THAT IN A MINORITY OF FACILITIES THE SYSTEM IS FAILING TO GIVE CONSUMERS CONFIDENCE THAT THE STANDARD OF CARE BEING DELIVERED IS ADEQUATE.

SINCE BECOMING PRESIDENT OF ALZHEIMER'S AUSTRALIA, PEOPLE HAVE SHARED WITH ME THEIR STORIES WITH ME. SOME TELL OF EXCELLENT CARE BUT OTHERS TELL OF PHYSICAL, PSYCHOLOGICAL AND SEXUAL ABUSE AS WELL AS INAPPROPRIATE USE OF PHYSICAL AND CHEMICAL RESTRAINTS.

MANY OF THESE PEOPLE SAY THEY'RE FEARFUL OF SPEAKING OUT PUBLICALLY ABOUT THEIR EXPERIENCE. I SUSPECT THERE MAY BE OTHERS WHO ARE SUFFERING IN SILENCE.

PEOPLE ARE RELUCTANT TO TAKE ACTION FOR FEAR THEY WILL LOSE THEIR PLACE.

THERE ARE ALWAYS TWO SIDES TO A STORY, BUT I THINK THERE'S ENOUGH EVIDENCE TO JUSTIFY RAISING THE ISSUE.

AND I DO WONDER WHY THERE IS SUCH VARIABILITY IN DEMENTIA CARE IN THE SECTOR. WHY DO SOME FACILITIES SEEM TO DO IT SO WELL EVEN WITHIN THE CURRENT FUNDING CONSTRAINTS, WHILE OTHERS STRUGGLE?

I ACCEPT THAT THE ISSUES AROUND QUALITY ARE A SYMPTOM OF A SYSTEM THAT IS OVER-STRETCHED, UNDERFUNDED AND WITH AN INADEQUATE INVESTMENT IN THE SKILLS OF STAFF, ESPECIALLY IN CARING FOR THE NEEDS OF PEOPLE WITH THE BEHAVIOURAL AND PSYCHOLOGICAL SYMPTOMS OF DEMENTIA.

WE ALL UNDERSTAND THAT EVEN IN THE BEST OF SETTINGS CRITICAL INCIDENTS CAN OCCUR. IF WE SHARE OUR EXPERIENCES AND LEARN FROM THESE INCIDENTS IT WILL HELP US DELIVER IMPROVED CARE OUTCOMES FOR RESIDENTS.

OF COURSE THERE IS A NEED FOR BETTER RESOURCING FOR THE SECTOR AND THERE'S A NEED ALSO FOR AN INDEPENDENT COST OF CARE STUDY TO DETERMINE THE TRUE COST OF PROVIDING HIGH QUALITY CARE.

BUT WHILE FUNDING ISSUES ARE IMPORTANT EQUALLY SO IS THE LEADERSHIP AND CULTURE THAT RESPECTS FOR THE RIGHTS AND DIGNITY OF THE OLDER PERSON. COMMON DECENCY AND RESPECT COSTS NOTHING.

IF WE ARE TO MEET THE NEEDS OF THE INCREASING NUMBER OF OLDER ADULTS IN AUSTRALIA – AND THOSE FROM THE BABY BOOMER GENERATION WHO HAVE VERY DIFFERENT EXPECTATIONS – WE'RE GOING TO NEED A DIFFERENT MINDSET.

MY VISION IS FOR AN AGED CARE SYSTEM THAT FOCUSES NOT JUST ON CARE BUT ON PSYCHOSOCIAL AND CULTURAL NEEDS AS WELL.

WE WANT RESIDENTIAL CARE FACILITIES AND COMMUNITY CARE SERVICES THAT PROVIDE NOT JUST THE BASIC REQUIREMENTS OF BATHING, FOOD AND MEDICATION, BUT ALSO OPPORTUNITIES FOR SOCIAL AND COMMUNITY ENGAGEMENT AND ACCESS TO APPROPRIATE CULTURAL OPPORTUNITIES.

AGED CARE FACILITIES SHOULD BE INTERESTING AND ENGAGING PLACES TO LIVE BUT ALL TOO OFTEN WE HEAR STORIES OF PEOPLE BECOMING DISENGAGED AND WITHERING AWAY AFTER THEY ENTER CARE.

I HOPE WE SHARE A VISION FOR A SYSTEM WHERE ENTERING CARE BRINGS NEW OPPORTUNITIES FOR SOCIAL ENGAGEMENT AND FOR MAXIMISING STRENGTHS AND ABILITIES.

UNLESS THERE IS A COMING TOGETHER OF CONSUMERS, PROVIDERS AND STAFF ON THE ACTION THAT'S NEEDED WE WON'T BE ABLE TO ACHIEVE THIS.

THE AGED CARE REFORMS HOLD THE PROMISE OF SOME POSITIVE STEPS TO ADDRESS QUALITY – SUCH AS THE DEVELOPMENT OF QUALITY INDICATORS FOR RESIDENTIAL AGED CARE FROM NEXT JULY AND THEN LATER FOR COMMUNITY CARE.

BUT THE REFORMS DON'T GO FAR ENOUGH IN RECOGNISING THE CONCERNS CONSUMERS HAVE ABOUT THE QUALITY OF RESIDENTIAL AGED CARE AND THE REGULATORY SYSTEM.

THE OBJECTIVE OF THE REPORT I'M LAUNCHING TODAY IS TO ARTICULATE THOSE CONCERNS; TO SET OUT FOR DISCUSSION POSSIBLE STRATEGIES TO ADDRESS THEM AND TO SEEK A HIGHER PRIORITY FOR TACKLING THEM.

THEY INCLUDE:

- **USE OF CHEMICAL AND PHYSICAL RESTRAINTS**
- **PHYSICAL ASSAULTS**
- **THE CURRENT LEVELS OF FUNDING**
- **INADEQUATE STAFFING LEVELS AND SKILLS MIX**
- **INADEQUATE ACCESS TO GOOD END OF LIFE CARE**
- **THE EFFECTIVENESS OF ACCREDITATION AND COMPLAINTS PROCESSES**
- **THE LACK OF TRANSPARENCY AND INFORMATION ON QUALITY IN RESIDENTIAL CARE.**

THE ISSUES ARE NOT NEW AND NEITHER ARE SOME OF THE STRATEGIES, AND MANY PROVIDERS ARE ALREADY TAKING ACTION THEMSELVES IN THE PURSUIT OF GOOD QUALITY CARE.

WE PROPOSE TWO LINES OF ACTION. FIRSTLY, TO ENSURE MINIMUM STANDARDS ARE IN PLACE AND BEING UPHELD FOR ALL RESIDENTS. URGENT AND SHORT TERM STRATEGIES THAT MIGHT BE CONSIDERED INCLUDE

- **EXPANDING MANDATORY REPORTING OF ALLEGED ASSAULTS TO INCLUDE SITUATIONS WHERE THE ALLEGED PERPETRATOR HAS A COGNITIVE IMPAIRMENT.**
- **EXPANDING THE AGED CARE STANDARDS TO REQUIRE PROVIDERS TO ENCOURAGE RESIDENTS TO COMPLETE ADVANCE CARE PLANS.**
- **ENCOURAGING PROVIDERS TO ENSURE ACCESS TO APPROPRIATE END OF LIFE CARE THROUGH STAFF TRAINING AND DEVELOPING A PALLIATIVE CARE PLAN WITH RESIDENTS AND THEIR FAMILIES.**
- **EXPANDING THE REACH OF THE COMMUNITY VISITORS SCHEME.**
- **ENSURING THAT COMPLAINTS THAT RELATE TO SERIOUS ISSUES AROUND USE OF MEDICATIONS, RESTRAINT OR ASSAULT ARE HANDLED PROMPTLY.**
- **INCREASING AWARENESS OF CONSUMERS ABOUT THE ROLE OF THE COMPLAINTS SCHEME AND THE NATIONAL AGED CARE ADVOCACY PROGRAM.**

SECONDLY, TO DEVELOP A MORE CONSUMER-ORIENTATED SYSTEM BY A GREATER INVOLVEMENT OF CONSUMERS IN THE MONITORING, ASSESSMENT AND COMPLAINTS PROCESSES.

THE AGED CARE REFORMS REPRESENT A SHIFT TOWARDS GREATER CONSUMER EMPOWERMENT, AND CONSUMERS ARE EAGER FOR THIS TO EXTEND INTO THE MONITORING OF THE SYSTEM.

CONSUMERS ARE SCEPTICAL ABOUT THE COMPLAINTS SCHEME AND THE ACCREDITATION PROCESS. AS I MENTIONED EARLIER MANY CONSUMERS ARE AFRAID TO CONTACT THE COMPLAINTS SCHEME AS THEY THINK THERE WILL BE RETRIBUTION FROM STAFF AT THE FACILITY.

SIMILARLY, MANY OF THEM ARE SCEPTICAL OF THE ACCREDITATION PROCESS AND QUESTION THE VALUE OF ANNOUNCED VISITS. IT MAKES SENSE TO ME TO EXPLORE WAYS OF INVOLVING CONSUMERS IN MONITORING STANDARDS AND RESPONDING TO COMPLAINTS.

I BELIEVE THE NEW QUALITY AGENCY AND THE SCHEME WOULD BENEFIT FROM CONSUMER EXPERIENCE AND EXPERTISE, AND CONSUMERS WILL GAIN A BETTER UNDERSTANDING AND CONFIDENCE IN THE ACCREDITATION AND COMPLAINTS PROCESS.

THERE ARE ISSUES TO WORK OUT AROUND THE ROLE OF CONSUMERS AND WHETHER THEY SHOULD ACT AS MEMBERS OF THE ASSESSMENT TEAM OR IN AN ADVISORY ROLE. CONSIDERATION ALSO NEEDS TO BE GIVEN TO TRAINING, EDUCATION AND MANAGING CONFLICTS OF INTEREST.

OUR REPORT PROVIDES AN OVERVIEW OF HOW THIS APPROACH IS WORKING OVERSEAS. IN THE UK, FOR EXAMPLE, THE 'EXPERTS BY EXPERIENCE' PROGRAM SUPPORTS CONSUMER INVOLVEMENT IN THE AUDITING AND ACCREDITATION PROCESS IN HEALTH CARE AND MENTAL HEALTH FACILITIES.

THE FEEDBACK HAS BEEN OVERWHELMINGLY POSITIVE – DUE TO THEIR FIRST-HAND EXPERIENCE WITH SERVICES, CONSUMERS ARE BETTER PLACED TO IDENTIFY WHAT THE KEY QUESTIONS AND ISSUES ARE AND TO CAPTURE INVALUABLE INFORMATION THAT MIGHT OTHERWISE GO UNDETECTED DURING STANDARD AUDITING PROCESSES.

IT'S ENCOURAGING THAT THE AUSTRALIAN STANDARDS AND ACCREDITATION AGENCY HAS ALREADY BEGUN LOOKING AT HOW CONSUMERS CAN BE MORE INVOLVED IN ACCREDITATION IN AUSTRALIA.

I LOOK FORWARD TO SEEING THE OUTCOMES OF THIS PILOT WORK AND I'M EXCITED ABOUT GETTING CONSUMERS MORE DIRECTLY INVOLVED IN THESE PROCESSES.

ANOTHER STRATEGY IS TO INCLUDE CONSUMER SATISFACTION SURVEYS AS PART OF THE INFORMATION AVAILABLE ON EACH FACILITY ON THE MY AGED CARE WEBSITE. SOME PROVIDERS ALREADY VALUE THIS TYPE APPROACH WITHIN THEIR CONTINUOUS IMPROVEMENT PROGRAMS.

IF I WERE CHOOSING A FACILITY I WOULD WANT TO KNOW THE VIEWS OF RESIDENTS AND FAMILY CARERS WHO HAVE EXPERIENCE OF THE FACILITY.

THIS PROBABLY WILL MEAN THAT BRANDING AND MARKETING WILL BECOME MORE IMPORTANT TO THE WAY YOU DO BUSINESS. EVERYONE THINKS THEY KNOW ABOUT MARKETING BUT IT IS A SPECIALISED ACTIVITY. LIKE EVERYTHING TO DO WITH BUSINESS IT REQUIRES A PLAN. YOU WILL NEED TO DETERMINE YOUR EDGE OF DIFFERENCE AND PRESENT IT TO THE MARKETPLACE.

THE QUALITY OF RESIDENTIAL CARE REPORT IS JUST THE BEGINNING OF OUR WORK ON QUALITY. CONSUMER ORGANISATIONS LIKE OURS SHOULD BE WORKING WITH THE PEAK AGED CARE BODIES TO COME UP WITH POINTS OF AGREEMENT ON HOW WE CAN MOVE FORWARD TO IMPROVE THE QUALITY OF CARE, REDUCE UNNECESSARY RED-TAPE, AND INVOLVE CONSUMERS IN ASSESSING QUALITY. I'D LIKE TO THINK THAT WE CAN WORK TOGETHER CONSTRUCTIVELY ON THESE ISSUES.

AT THE ROUNDTABLE I MENTIONED EARLIER THERE WAS MUCH DISCUSSION OF THE INTERPLAY BETWEEN MEDICAL ISSUES AND THE SOCIAL ENVIRONMENT.

EVERYONE RECOGNISED THAT DEMENTIA IS NOT JUST A MEDICAL CONDITION AND THAT A DIAGNOSIS OF DEMENTIA OFTEN RESULTS IN STIGMA AND SOCIAL ISOLATION.

RESEARCH EVIDENCE SUPPORTS THIS VIEW. AN AUSTRALIAN-WIDE SURVEY IN 2011 FOUND THAT 44 PER CENT OF PEOPLE SURVEYED BELIEVED THAT PEOPLE WITH DEMENTIA ARE DISCRIMINATED AGAINST OR TREATED UNFAIRLY; 22 PER CENT SAID THEY WOULD FEEL UNCOMFORTABLE SPENDING TIME WITH SOMEONE WHO HAD DEMENTIA.

A STUDY LAST YEAR SHOWED THAT APPROXIMATELY ONE QUARTER OF THOSE SURVEYED WOULD AVOID SEEKING ASSISTANCE FOR MEMORY PROBLEMS; 60 PER CENT 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.

FOR MANY PEOPLE LIVING WITH DEMENTIA NOT HAVING THE OPPORTUNITY TO REMAIN ENGAGED IN THEIR COMMUNITIES IS A SHAMEFUL REALITY. FOR INSTANCE, IT'S IMPORTANT THAT PEOPLE WITH DEMENTIA WHO ENJOY BOWLING AND GOLF SHOULD BE ABLE TO CONTINUE THEIR ACTIVITIES FOR AS LONG AS POSSIBLE.

THE SOLUTIONS AREN'T ROCKET SCIENCE BUT THEY DO REQUIRE IMAGINATION. FOR EXAMPLE, A BUDDY SYSTEM IN SPORTING CLUBS MIGHT HELP. THIS KIND OF LATERAL THINKING IS AT THE HEART OF THE CONCEPT OF DEMENTIA- FRIENDLY COMMUNITIES AND THE VOICES OF THOSE LIVING WITH DEMENTIA IS CRITICAL TO ACHIEVING THIS.

THE OBJECTIVES OF DEMENTIA- FRIENDLY COMMUNITIES ARE TO DEVELOP WAYS TO PROMOTE SOCIAL INCLUSION AS WELL AS AWARENESS OF DEMENTIA.

THE DEMENTIA- FRIENDLY IDEA IS GAINING INTERNATIONAL MOMENTUM WITH INNOVATIVE WORK TAKING PLACE IN THE UNITED KINGDOM, JAPAN AND BELGIUM. AUSTRALIA TOO SHOULD BE AT THE FOREFRONT OF MAKING DEMENTIA-FRIENDLY COMMUNITIES A REALITY. THIS IS ONE OF OUR IMPORTANT GOALS FOR 2014.

WE ARE COMMITTED TO ACHIEVING THIS SOCIAL CHANGE BY WORKING WITH PEOPLE LIVING WITH DEMENTIA, BY LISTENING TO THEIR VIEWS ABOUT HOW COMMUNITIES AND ORGANISATIONS CAN MAKE THEIR JOURNEY EASIER AND TO CREATE OPPORTUNITIES FOR THEM TO BE ENGAGED WITH THE COMMUNITY IN WHICH THEY LIVE AND TO CONTRIBUTE IN A MEANINGFUL WAY.

WHEN I REFLECT ON THE ALMOST THREE YEARS THAT I HAVE BEEN PRESIDENT OF ALZHEIMER'S AUSTRALIA THE THING THAT STRIKES ME IS HOW MUCH PROGRESS WE HAVE MADE IN THE AGED CARE SECTOR AND HOW MUCH FURTHER WE HAVE TO GO.

THE AGED CARE REFORMS HAVE BROUGHT MANY EXCITING OPPORTUNITIES. WE NOW HAVE SOME FUNDING TO BEGIN TO ADDRESS DEMENTIA ACROSS BOTH THE HEALTH AND AGED CARE SYSTEM.

THE AGED CARE SYSTEM IS MORPHING INTO NEW MODEL THAT HAS GREATER FOCUS ON CHOICE, SUSTAINABILITY AND COMMUNITY CARE.

BUT WE ARE STILL JUST AT THE BEGINNING. REAL REFORM OF THE SYSTEM WILL BE A SLOW, GRADUAL AND, AT TIMES, PAINFUL PROCESS.

IF THE REFORM PROCESS IS TO SURVIVE THE CHANGING POLITICAL ENVIRONMENT WE MUST, AS A SECTOR, JOIN TOGETHER AND CONTINUE TO PRESS THE NEED FOR REFORM.

THERE IS SO MUCH THAT UNITES US. WE ALL WANT BETTER CARE AND SUPPORT FOR OLDER PEOPLE IN OUR SOCIETY IN BOTH COMMUNITY AND RESIDENTIAL CARE.

WE ALL KNOW THE IMPACT THAT GOOD CARE HAS ON THE QUALITY OF LIFE OF AN OLDER PERSON.

THAT'S WHY I AND MY COLLEAGUES AT ALZHEIMER'S AUSTRALIA BELIEVE QUALITY CARE FOR ALL OLDER AUSTRALIANS WHO NEED IT MUST BE ONE OF THE PRIMARY DRIVERS OF THE REFORMS

WE MAY DIFFER IN SOME OF THE STRATEGIES AND APPROACHES BUT GIVEN OUR COMMON GOALS I AM CONFIDENT THAT WE CAN PRESENT A UNITED FRONT AND WORK TO RAISE COMMUNITY AND POLITICAL AWARENESS OF THE CRITICAL IMPORTANCE OF GIVING PRIORITY TO QUALITY ISSUES IN THE REFORM OF AGED CARE.

I HOPE THE TWO REPORTS I'VE LAUNCHED TODAY WILL ASSIST IN THAT OBJECTIVE. YOU WILL FIND COPIES ON THE ALZHEIMER'S AUSTRALIA FIGHT DEMENTIA WEBSITE AND COPIES OF *THE QUALITY OF RESIDENTIAL AGED CARE* ON THE ALZHEIMER'S VICTORIA STAND.

AS I OFTEN REMIND PEOPLE NOT EVERYONE GETS TO BE OLD. YOU HAVE TO BE LUCKY TO GET TO OLD. HOW WOULD WE WISH TO BE TREATED IF WE NEEDED QUALITY CARE IN OUR OLDER YEARS? WE ALL KNOW THE ANSWER – WITH RESPECT AND DIGNITY.

THE FUTURE OF SENIORS IN AUSTRALIA RELIES ON US MAKING THE RIGHT DECISIONS AND OF OUR WORKING TOGETHER TO DELIVER THE BRIGHTEST POSSIBLE FUTURE FOR ALL OLDER AUSTRALIANS... AND I INCLUDE EVERYONE HERE THIS AFTERNOON IN THAT DESCRIPTION.

THANK YOU