

The Art of Being Positive

**THE ART OF BEING POSITIVE
ALZHEIMER'S AUSTRALIA WA PUBLIC LECTURE SERIES 2013**

**THE UNIVERSITY CLUB
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I AM DELIGHTED TO BE BACK IN WESTERN AUSTRALIA AND TO HAVE THE OPPORTUNITY TO SPEAK AT THIS PUBLIC LECTURE THIS EVENING, ON THE POWER OF BEING POSITIVE...

...OF BEING POSITIVE ABOUT THE OUTLOOK FOR DEMENTIA – FOR TREATMENTS AND A CURE TO BE DEVELOPED; FOR AUSTRALIANS TO ACT POSITIVELY IN THE INTERESTS OF THEIR OWN HEALTH AND ADOPT ALZHEIMER’S AUSTRALIA RISK REDUCTION STRATEGIES; AND TO CREATE THE ENGAGEMENT OF PEOPLE WITH DEMENTIA WITH THE COMMUNITY IN WHICH THEY LIVE BY ENCOURAGING AUSTRALIA TO BECOME A DEMENTIA-FRIENDLY SOCIETY.

WE MUSTN’T LET THE NEGATIVITY OF DEMENTIA AS AN INEVITABLE PART OF AGEING TO TRIUMPH. DEMENTIA IS NOT A NATURAL PART OF AGEING. IT IS A CHRONIC DISEASE

AT ALZHEIMER’S AUSTRALIA THERE HAS BEEN A QUIET SENSE OF OPTIMISM BY DEVELOPMENTS IN AUSTRALIA OVER THE LAST THREE YEARS – SUCH AS DEMENTIA BECOMING A NATIONAL HEALTH PRIORITY AND THE NEW FEDERAL GOVERNMENT COMMITTING \$200 MILLION OVER FIVE YEARS TO DEMENTIA RESEARCH.

UP UNTIL NOW DEMENTIA RESEARCH HAS BEEN GROSSLY UNDERFUNDED IN AUSTRALIA.

RESEARCH IS VITAL IF WE ARE TO UNLOCK THE MYSTERIES OF THE BRAIN AND FIND OUT WHY PEOPLE GET DEMENTIA AND WHY IT ATTACKS THE BRAIN IN THE WAY THAT IT DOES.

AT LAST DEMENTIA IS WELL AND TRULY ON THE MAP IN THIS COUNTRY.

I HAVE WITNESSED A SIGNIFICANT CHANGES BOTH POLITICALLY AND IN THE COMMUNITY AWARENESS OF DEMENTIA IN THE SIX YEARS I HAVE BEEN OFFICIALLY INVOLVED IN THE FIGHT AGAINST THE DISEASE – FIRST AS A MEMBER OF THE ADVISORY COUNCIL OF ALZHEIMER’S NSW; AND CURRENTLY AS NATIONAL PRESIDENT OF ALZHEIMER’S AUSTRALIA, A POSITION I HAVE HELD NOW FOR ALMOST THREE YEARS.

BUT MY INVOLVEMENT IN DEMENTIA GOES BACK BEYOND THAT. I WAS THE PRINCIPAL CARER FOR MY FATHER WHO HAD VASCULAR DEMENTIA, THE SECOND MOST COMMON DEMENTIA AFTER ALZHEIMER’S DISEASE. I CARED FOR DAD FOR SEVEN YEARS.

AS PRESIDENT IT HASN’T ALWAYS BEEN EASY TO ESCAPE MY MEMORIES OF FATHER AND HIS DEMENTIA. IN FACT MY PERSONAL DECISION IS NOT TO TRY TO ESCAPE BUT TO LEARN FROM THAT TIME IN MY PERSONAL AND WORKING LIFE.

I HAVE A TREASURE TROVE OF MEMORIES FROM THAT TIME. I WOULDN'T FOR ONE MOMENT WANT TO ROMANTICISE THOSE YEARS – I DOUBT ANY OTHER FAMILY CARER WOULD WANT TO DO SO EITHER – BUT YOU DO LEARN FROM ALL EXPERIENCES IN LIFE AND THOSE YEARS WITH DAD WERE SPECIAL.

I NEVER KNEW QUITE WHO WAS IN CHARGE!

IF, THROUGHOUT OUR LIVES, OUR RELATIONSHIPS WITH OTHERS CAN BE COMPLEX I WOULD SUGGEST JUST TRY THE EXPERIENCE OF LIVING AND BREATHING DEMENTIA 24 HOURS A DAY.

WE OFTEN CASUALLY SAY THAT EVERY INDIVIDUAL IS UNIQUE AND WE THINK WE MEAN IT, AND KNOW WHAT IT MEANS, BUT IT ISN'T UNTIL YOU CARE FOR SOMEONE YOU LOVE THAT THE MEANING BECOMES CLEAR.

HUMOUR WAS AN ESSENTIAL ELEMENT OF SPENDING TIME WITH DAD.

LIKE THE TIME DAD HAD TO GO TO HOSPITAL TO HAVE A PACEMAKER FITTED. ALL WENT WELL, BUT DAD HAD TO SPEND A FEW DAYS IN HOSPITAL – HIS HEART WAS BEING MONITORED, HE HAD ALL SORTS OF ATTACHMENTS ETC....

HE DECIDED HOWEVER THAT HE WANTED TO GO HOME. HE SLIPPED EVERYTHING OFF AND BROKE WHATEVER HE COULDN'T UNDO (HE WAS PHYSICALLY STRONG) – THE HOSPITAL STAFF COULDN'T CALM HIM DOWN, I WAS CALLED....

WHEN I GOT THERE DAD SAID TO ME: “STRANGE SHIP THIS, WHEN IT DOCKS THEY WON’T LET YOU OFF.” I MANAGED TO TALK HIM INTO STAYING AND ON THE WEEKEND PICKED HIM UP TO DRIVE HIM HOME.

I HAD MY DAUGHTER KATE WITH ME AND WHEN WE GOT TO DAD’S PLACE WE HAD A CUP OF TEA IN THE KITCHEN.

KATE TOLD HER GRANDFATHER THAT SHE THOUGHT HE WAS LOOKING WELL.

“I AM,” SAID DAD, “I’VE BEEN ON A CRUISE.”

IT IS SO IMPORTANT THAT WE CAN ALL LAUGH WITH PEOPLE WITH DEMENTIA. WHAT BETTER WAY TO REDUCE THE STIGMA AND SOCIAL ISOLATION THAN TO LAUGH. BUT, WE WALK A DELICATE LINE BETWEEN LAUGHING WITH PEOPLE WITH DEMENTIA AND LAUGHING AT THEM.

I KNOW NO ONE HERE WOULD EVER LAUGH AT A PERSON WITH DEMENTIA.

I’VE OFTEN BEEN ASKED WHAT I THINK OF PROGRAMS LIKE “MOTHER AND SON”. ... ACTUALLY, I CAN THINK OF NO BETTER WAY OF PORTRAYING THE COMPLEXITY AND INTIMACY OF THE CHANGING FAMILY RELATIONSHIPS THAT RESULT FROM AGEING AND DEMENTIA.

AT THE TIME AND, IN RETROSPECT, PROGRAMS SUCH AS “MOTHER AND SON” REMINDED ME OF THE HAPPIEST AND THE SADDEST TIMES WITH DAD.

WATCHING MAGGIE WASHING STRAWBERRIES WITH DETERGENT;
SPRAYING ARTHUR’S SHIRT WITH PAINT INSTEAD OF WATER; THE MORE
CONFRONTING EPISODE ABOUT HER ANXIETY ABOUT HER LATE
HUSBAND’S WHEREABOUTS...ARE EPISODES THAT ALL RING TRUE AND IT
SEEMS TO ME THEY ARE HANDLED MORE EASILY WITH HUMOUR.

THE ACTOR, MICHAEL PATON, WHOSE MOTHER SUFFERED FROM
DEMENTIA, EXPLORED THE TOPIC OF DEMENTIA THROUGH HIS
CHARACTER ON TV’S “PACKED TO THE RAFTERS”. HIS CHARACTER’S
BATTLE WITH THE DISEASE WAS ONE OF THE SHOW’S MAJOR STORIES.

OF COURSE WE CAN’T ALLOW HUMOUR OR MEDIA DRAMA TO MASK THE
SERIOUS SIDE TO THESE STORIES. FOR INSTANCE, I NEVER KNEW WHAT
MOOD DAD WAS GOING TO BE IN WHEN I ARRIVED OR WHERE HE WAS
GOING TO BE.

THROUGH ALZHEIMER’S AUSTRALIA AND THE TELLING THE STORIES OF
PEOPLE WITH DEMENTIA WE HAVE TO GET ACROSS AN UNDERSTANDING
OF THE HUMOUR, FRUSTRATION AND DESPAIR THAT ACCOMPANIES
DEMENTIA AND HOW IMPORTANT IT IS TO RESPOND TO THE NEEDS OF THE
PERSON AND NOT JUST THE SYMPTOMS OF THE CONDITION.

I THINK THE WORD CARE IS A PROBLEM. I NEVER THOUGHT OF MYSELF AS A CARER – I WAS A DAUGHTER AND WE ALL KNOW HOW SPECIAL AND OCCASIONALLY DIFFICULT FATHER AND DAUGHTER RELATIONSHIPS CAN BE.

CARE IMPLIES DEPENDENCE RATHER THAN BUILDING ON A PERSON'S STRENGTHS. WE ALL BEGIN TO DO THINGS FOR THE PERSON WITH DEMENTIA AND MAKING DECISIONS FOR THEM LONG BEFORE THEY LOSE CAPACITY TO DO SUCH THINGS FOR THEMSELVES.

THIS IS WHY I AM PASSIONATE ABOUT THE WORK ALZHEIMER'S AUSTRALIA IS DOING TO PROMOTE MONTESSORI TECHNIQUES IN DEMENTIA CARE AND SUPPORT SO FASCINATING.... EXPLORING WAYS IN WHICH WE CAN BUILD ON THE STRENGTHS OF THE PERSON WITH DEMENTIA AND HELPING THEM TO ENGAGE WITH US AND THE WORLD AROUND THEM.

WE KNOW SO LITTLE ABOUT HOW PEOPLE WITH DEMENTIA PERCEIVE THE WORLD. HOW CAN WE ENSURE THAT DECISION MAKING RESPONDS TO THEIR OFT QUOTED DEMAND "NOTHING ABOUT US WITHOUT US."

IN A TRULY DEMENTIA-FRIENDLY WORLD WE WOULD TRY TO OBSERVE SOME SIMPLE RULES

- **ALWAYS TAKE DECISIONS WITH THE PERSON WHO HAS DEMENTIA FOR AS LONG AS YOU CAN**
- **AVOID FINISHING SENTENCES FOR PEOPLE WITH DEMENTIA AND UNDERSTAND THE BASICS OF HOW TO COMMUNICATE**

- **AND FOR A PARTNER OR DAUGHTER – KNOW WHEN TO GET HELP AND NEVER FEEL GUILTY ABOUT DOING SO**

I'M SURE MANY OF YOU KNOW THAT ALZHEIMER'S AUSTRALIA WESTERN AUSTRALIA WAS THE FIRST STATE-BASED ALZHEIMER'S ORGANISATION TO BE ESTABLISHED IN AUSTRALIA, WHICH WAS QUITE AN ACHIEVEMENT.

THIS HAPPENED JUST OVER 30 YEARS AGO AND IT WAS HARD WORK OF FAMILY CARERS, THOSE UNSUNG HEROES FOR THE MOST PART, WHO MADE IT POSSIBLE.

ALZHEIMER'S AUSTRALIA WA CHAIRMAN, CRAIG MASAREI, WHO ALSO SERVES AS TREASURER OF OUR NATIONAL BOARD, HAS ENSURED THE ORGANISATION HAS CONTINUED ITS STRONG LEADERSHIP ROLE IN KEY AREAS.

WA HAS WORKED WITH SERVICE PROVIDERS AND CONSUMERS TO DEVELOP A CONSULTANCY CAPACITY TO WORK ON NEW APPROACHES TO DEMENTIA CARE AND SUPPORT, SOMETHING I WILL TOUCH ON LATER.

IT HAS ALSO TAKEN A KEEN INTEREST IN THE POSSIBILITIES OF ASSISTED TECHNOLOGY TO SUPPORT PEOPLE WITH DEMENTIA LONG BEFORE OTHER ALZHEIMER'S ORGANISATIONS AND HAS BEEN ACTIVE IN PROMOTING GOOD DESIGN FOR PEOPLE WITH DEMENTIA IN DOMESTIC AND RESIDENTIAL CARE FACILITIES.

IT IS CRUCIAL ALZHEIMER'S AUSTRALIA DOESN'T JUST DELIVER THE BEST SERVICES IT CAN BUT ALSO ACHIEVES SYSTEM CHANGE IN THE DELIVERY OF CARE AND SUPPORT THROUGH ADVOCACY AND ESTABLISHING PARTNERSHIPS WITH HEALTH AND CARE SERVICE PROVIDERS.

IF WE ARE TO IMPROVE THE QUALITY OF LIFE OF PEOPLE WITH DEMENTIA AND THEIR FAMILY CARERS WE HAVE TO FOCUS ON MAKING THE HEALTH AND CARE SYSTEM MORE DEMENTIA FRIENDLY. THE COMPETING DEMANDS ON THE HEALTH AND CARE SYSTEM MAKE THIS A HUGE TASK BUT THERE ARE SIGNS THAT OUR MESSAGE IS GETTING THROUGH.

WE KNOW WE HAVE TO BE DETERMINED AND POSITIVE IN OUR ADVOCACY.

OUR FIGHT DEMENTIA CAMPAIGN WAS BORN OUT OF FRUSTRATION AND DISAPPOINTMENT.

FRUSTRATION THAT IN SPITE OF OUR STRONG ADVOCACY AND WELL WRITTEN SUBMISSIONS, THE PRODUCTIVITY COMMISSION DID NOT MAKE A SINGLE RECOMMENDATION ON DEMENTIA IN ITS FINAL REPORT ON CARING FOR OLDER AUSTRALIANS.

AND DISAPPOINTMENT THAT THE 2011 BUDGET INSTEAD OF BUILDING ON THE 2005 DEMENTIA INITIATIVE THREATENED IT BY THE INTRODUCTION OF NEW FUNDING ARRANGEMENTS IN THE DEPARTMENT OF HEALTH AND AGEING.

ALTHOUGH WE CELEBRATED THE PROPOSED REFORMS FOR AGED CARE WE SIMPLY COULDN'T UNDERSTAND WHY THERE WASN'T A SINGLE RECOMMENDATION ON DEMENTIA OR ANY RECOGNITION OF THE NEED TO TACKLE DEMENTIA IN BOTH THE AGED CARE AND HEALTH SYSTEMS.

THE LAUNCH OF THE FIGHT DEMENTIA CAMPAIGN AT PARLIAMENT HOUSE, CANBERRA, IN OCTOBER 2011, SAW MORE THAN 500 PEOPLE FROM ALL OVER AUSTRALIA, MANY FROM WESTERN AUSTRALIA; MEET WITH POLITICIANS INCLUDING THE THEN MINISTER FOR MENTAL HEALTH AND AGEING, MARK BUTLER.

WE APPRECIATED THE ACTIVE SUPPORT OF CARERS AUSTRALIA AND THE AUSTRALIAN NURSING FEDERATION AS WELL AS SERVICE PROVIDERS SUCH AS BUPA HEALTH SERVICES AND ANGLICARE.

PERHAPS SOME OF YOU HERE WHO WERE AT THE MARCH. I SUSPECT THAT LIKE ME IT WAS ONE OF THOSE MOMENTS YOU WILL NEVER FORGET.

IT WAS MY FIRST EVER PROTEST MARCH. I MUST CONFESS I RATHER ENJOYED IT.

THERE HAD BEEN NOTHING IN MY JOB DESCRIPTION AS PRESIDENT OF ALZHEIMER'S AUSTRALIA THAT SUGGESTED I WOULD BE REQUIRED TO MAN THE RAMPARTS.

SUE PIETERS-HAWKE – THE DAUGHTER OF FORMER PRIME MINISTER BOB HAWKE AND HAZEL HAWKE, WHO DIED EARLIER THIS YEAR FROM ALZHEIMER’S DISEASE, IS ONE OF OUR AMBASSADORS. SHE WAS MARCHING; SHE KNEW ALL ABOUT PROTEST MARCHES AND SHE SHOWED THE REST OF US THE ROPES.

**HOLDING A HUGE FIGHT DEMENTIA BANNER WE BEGAN TO CHANT ...
WHAT DO WE WANT? MORE MONEY FOR DEMENTIA. WHEN DO WE WANT IT?
NOW.**

AT ONE POINT SUE SHOUTED OVER TO ME: “HEY ITA, YOU’RE NOT A VIRGIN MARCHER ANY MORE”.

“YES BUT SUE,” I SHOUTED BACK “I NEVER THOUGHT I’D LOSE MY VIRGINITY ON THE LAWNS OF PARLIAMENT HOUSE.”

NOT LONG AFTER, ALONG WITH MY CEO, GLENN REES, WE CALLED ON THE THEN PRIME MINISTER, JULIA GILLARD IN CANBERRA TO RAISE OUR CONCERNS. SHE SEEMED SYMPATHETIC AND WAS INTERESTED TO LEARN ABOUT THE LINKS BETWEEN DIABETES AND DEMENTIA.

SHE SEEMED SLIGHTLY SURPRISED TOO THAT IT HAD PROVED SO DIFFICULT OVER SO MANY YEARS TO ENGAGE PUBLIC HEALTH POLICY IN THE ISSUE OF DEMENTIA FOR SUCH THINGS AS TIMELY DIAGNOSIS AND CARE IN HOSPITALS.

WE KNEW WE HAD TO CONTINUE TO CAMPAIGN VIGOROUSLY IF WE WERE TO GET THE RIGHT DECISIONS IN THE 2012 BUDGET. WE RELEASED THE RESULTS OF AGED CARE CONSULTATIONS WITH PEOPLE WITH DEMENTIA AND THEIR FAMILY CARERS ON 9 APRIL 2012 – EASTER MONDAY. IT ATTRACTED A CUMULATIVE MEDIA AUDIENCE OF 16 MILLION AUSTRALIANS!

A FEW WEEKS LATER THE *LIVING LONGER. LIVING BETTER.* AGED CARE REFORM PACKAGE WAS ANNOUNCED BY PRIME MINISTER GILLARD AND MINISTER BUTLER. IT NOT ONLY RESPONDED TO OUR ADVOCACY ON AGED CARE BUT ALSO ON DEMENTIA.

IT INCLUDED:

- **A COMMITMENT TO MAKE DEMENTIA A NATIONAL HEALTH PRIORITY. BY AUGUST THAT YEAR.**
- **FUNDING TO SUPPORT INITIATIVES TO IMPROVE THE TIMELY DIAGNOSIS OF DEMENTIA.**
- **FUNDING TO IMPROVE THE CARE OF DEMENTIA PATIENTS IN HOSPITALS.**
- **FUNDING FOR A *DEMENTIA RISK REDUCTION PROGRAM.***
- **AND DEMENTIA SUPPLEMENTS TO RECOGNISE THE *ADDITIONAL COSTS OF DEMENTIA CARE* IN BOTH COMMUNITY AND RESIDENTIAL CARE SERVICES.**

TO ACHIEVE ALL OF THESE OBJECTIVES THE GOVERNMENT ANNOUNCED A COMMITMENT TO \$270 MILLION TO FIGHT DEMENTIA OVER THE NEXT FIVE YEARS.

I'M PLEASED TO SAY THAT WE HAVE ALREADY SEEN ACTION IN THREE AREAS IN JUST 12 MONTHS.

- **AUSTRALIA'S HEALTH MINISTERS DECLARED DEMENTIA, A NATIONAL HEALTH PRIORITY IN AUGUST 2012.**
- **WE HAVE SEEN FUNDING USED TO SUPPORT THE EXCELLENT WORK OF THE AUSTRALIAN COMMISSION ON SAFETY AND QUALITY IN HEALTH CARE TO MAKE DEMENTIA CARE PART OF THEIR MANDATORY STANDARDS AS WELL AS DEVELOPING A RESOURCE ON DEMENTIA CARE IN ACUTE CARE.**
- **AND ALZHEIMER'S AUSTRALIA HAS RECEIVED FUNDING FOR OUR DEMENTIA RISK REDUCTION PROGRAM, "YOUR BRAIN MATTERS".**

IN SHORT WE ACHIEVED JUST ABOUT ALL WE HAD BEEN SEEKING IN TERMS OF POLICY AND FUNDING, EXCEPT THE FUNDING WE WERE SEEKING FOR DEMENTIA RESEARCH.

THIS LAST PIECE OF THE PUZZLE WAS PUT INTO PLACE FOLLOWING THE RECENT FEDERAL ELECTION WHEN THE COALITION COMMITTED TO PROVIDING \$200 MILLION OVER FIVE YEARS FOR DEMENTIA RESEARCH.

THIS IS TRULY WELCOME BECAUSE WITHOUT RESEARCH INTO THE CAUSE, CURE AND CARE OF DEMENTIA, WE CAN NOT GIVE AUSTRALIANS THE HOPE THEY NEED FOR THE FUTURE.

WE NEED TO FIND WAYS OF IDENTIFYING THOSE AT RISK AND THEN INTERVENING TO MODIFY THE PROGRESSION OF THE DISEASE.

AS I SAID EARLIER, WE NEED TO FIND OUT WHAT CAUSES DEMENTIA AND HOW AND WHY IT AFFECTS THE BRAIN THE WAY IT DOES.

ALZHEIMER'S AUSTRALIA IS LOOKING FORWARD TO WORKING WITH THE GOVERNMENT AND THE NATIONAL HEALTH AND MEDICAL RESEARCH COUNCIL – THE NHMRC – TO ENSURE THIS MONEY IS WELL INVESTED.

I AM SURE WE WOULD ALL LIKE TO LEAVE A LEGACY THAT BUILDS ON THE GREAT ACHIEVEMENTS OF MEDICAL AND SCIENTIFIC RESEARCH IN AUSTRALIA.

ALZHEIMER'S AUSTRALIA HAS PROPOSED THE ESTABLISHMENT OF A NEW NATIONAL DEMENTIA INSTITUTE THAT WOULD CREATE OPPORTUNITIES FOR AN INNOVATIVE APPROACH TO TACKLING DEMENTIA AND BRINGING TOGETHER LEADING THINKERS FROM FIELDS SUCH AS IMMUNOLOGY, DIABETES AND CARDIOVASCULAR DISEASE.

ALL TOO OFTEN RESEARCH, INCLUDING THAT DONE IN THE FIELD OF DEMENTIA, IS CONSTRAINED WHEN THE OBJECTIVE SHOULD BE TO ENSURE DIFFERENT DISCIPLINES CAN CONTRIBUTE TO WHAT IS ONE OF THE MAJOR MEDICAL CHALLENGES OF THIS CENTURY.

A NEW NATIONAL DEMENTIA INSTITUTE WOULD PROVIDE THE OPPORTUNITY OF DEMENTIA RESEARCH AND ENCOURAGE NEW RESEARCHERS TO ENTER A FIELD THAT HAS BEEN NEGLECTED FOR SO LONG.

IT IS ESSENTIAL THE NEW FUNDING IS USED TO DEVELOP DEMENTIA RESEARCH CAPACITY.

WITHOUT NEW RESEARCHERS, WE WON'T HAVE THE CAPACITY TO ANSWER THE MANY PRESSING QUESTIONS WE WILL FACE IN THE FUTURE.

A NATIONAL DEMENTIA INSTITUTE WOULD POSITION AUSTRALIAN RESEARCHERS TO COLLABORATE AND PARTNER MORE EFFECTIVELY WITH OVERSEAS RESEARCHERS WHOSE GOVERNMENTS HAVE SIMILARLY INVESTED IN RESEARCH.

WHEN I BECAME PRESIDENT OF ALZHEIMER'S AUSTRALIA I AGREED WITH THE CEO, GLENN REES, THAT WE WOULD GET DEMENTIA ON THE POLITICAL MAP AND ACTION TO TACKLE IT WITHIN THREE YEARS.

WE SEEM TO BE ON TRACK TO DO THAT. HOWEVER I AM REMINDED EVERY DAY HOW FAR WE STILL HAVE TO GO TO ACTUALLY TRANSLATE OUR ENCOURAGING POLICY AND FUNDING DECISIONS INTO IMPROVED CARE ON THE GROUND.

OF COURSE IT'S NOT ONLY IMPROVED CARE THAT'S IMPORTANT, SO TOO ARE THE ATTITUDES OF THE BROADER COMMUNITY TO DEMENTIA, AND THEIR UNDERSTANDING OF WHAT LIFE WITH DEMENTIA INVOLVES FOR PEOPLE WITH A DIAGNOSIS AND THEIR FAMILY CARERS.

THIS IS THE THOUGHT THAT DRIVES THE FIGHT DEMENTIA CAMPAIGN AND WILL SEE IT CONTINUE WITH THE NEW ABBOTT GOVERNMENT. WE ARE CURRENTLY WORKING ON A VISION FOR THE NEW GOVERNMENT ON WHAT IT MIGHT ACHIEVE IN RESPECT OF DEMENTIA.

WE HAVE LEARNT FROM OUR FIGHT DEMENTIA CAMPAIGN THE IMPORTANCE OF WELL EVIDENCED ADVOCACY POSITIONS, AND OF BEING FOCUSED AND POSITIVE IN THE WAY THEY ARE PRESENTED AT THE POLITICAL AND COMMUNITY LEVEL.

AS A JOURNALIST, A PARTICULAR FASCINATION FOR ME IS THE COMMUNICATION OF NEW IDEAS WITH A VIEW TO INFLUENCING CHANGES IN ATTITUDE IN THE COMMUNITY.

IN FRAMING OUR CAMPAIGN WE IT'S NECESSARY TO KEEP IN MIND THAT EVEN WITHIN ALZHEIMER'S AUSTRALIA PEOPLE WITH DEMENTIA WERE ONLY EMPOWERED TO SELF ADVOCATE FROM 2001; WHEN PEOPLE WITH DEMENTIA WERE EMPOWERED TO SPEAK AT CONFERENCES AND CONTRIBUTE TO THE ACTIVITIES AND GOALS OF ALZHEIMER'S AUSTRALIA.

THEIR INVOLVEMENT HAS BEEN CRUCIAL OVER THE LAST DECADE IN GETTING THE ATTENTION OF GOVERNMENT AND THE MEDIA ABOUT THE PREVALENCE OF DEMENTIA, ITS IMPACT ON AUSTRALIA'S HEALTH AND CARE SYSTEM AND EVEN MORE IMPORTANTLY, THE IMPACT IT HAS ON THE INDIVIDUAL WITH THE DIAGNOSIS AND ALSO THEIR FAMILY AND FRIENDS.

AT THE SAME TIME, WE NEED TO BE WARY OF GENERATING HEADLINES THAT DESCRIBE THE AGEING OF THE POPULATION AS A "DEMOGRAPHIC TIME BOMB" OR DECLARING AN "AGEING TSUNAMI" IS ON ITS WAY.

IF WE ARE TO ACHIEVE A CULTURE SHIFT IN AUSTRALIA AND A MORE POSITIVE APPROACH TO AGEING WITH A BETTER UNDERSTANDING OF DEMENTIA WE NEED TO RECOGNISE THE VALUE OF OLDER PEOPLE IN OUR SOCIETY.

JUST IMAGINE WHAT WE COULD ACHIEVE IF WE COULD TAP INTO THE WISDOM, EXPERIENCE AND CREATIVITY OF OLDER PEOPLE MORE THAN WE DO.

IN FRAMING A FIGHT DEMENTIA CAMPAIGN THAT WILL RESPOND TO THE PRIORITIES OF PEOPLE LIVING WITH DEMENTIA WE NEED TO BE POSITIVE AND TO FOCUS ON WHAT WE CAN DO TO IMPROVE THE QUALITY OF LIFE FOR PEOPLE WITH DEMENTIA.

THERE ARE A NUMBER OF WAYS TO ACHIEVE THIS POSITIVE APPROACH.

WE NEED TO:

- **INCREASE THE UNDERSTANDING OF DEMENTIA AS A PUBLIC HEALTH ISSUE.**
- **CARRY THIS PUBLIC HEALTH MESSAGE THROUGH INTO PREVENTIVE HEALTH POLICY.**
- **EMPOWER PEOPLE WITH DEMENTIA AND THEIR FAMILY CARERS TO MAKE CHOICES AND DECISIONS ABOUT HOW BEST THEIR NEEDS CAN BE MET.**
- **BRING TOGETHER GOVERNMENT, PROVIDERS, STAFF AND CONSUMERS TO DEVELOP STRATEGIES THAT PROMOTE BETTER QUALITY DEMENTIA CARE.**
- **AND PROMOTE SOCIAL INCLUSION OF PEOPLE WITH DEMENTIA THROUGH DEMENTIA FRIENDLY COMMUNITIES AND ORGANISATIONS.**

THE ENDURING COMMUNITY VIEW OF DEMENTIA IN AUSTRALIA AND INDEED WORLDWIDE IS THAT DEMENTIA IS AN INEVITABLE PART OF AGEING. THIS IN ITSELF HAS GENERATED NEGATIVITY, STIGMA AND A SENSE OF HOPELESSNESS.

THIS BELIEF IS WIDESPREAD EVEN THOUGH WE KNOW THAT THREE IN FOUR PEOPLE AGED OVER 85 WILL NOT HAVE DEMENTIA.

A STUDY LAST YEAR SHOWED APPROXIMATELY ONE QUARTER OF THOSE SURVEYED WOULD AVOID SEEKING ASSISTANCE FOR MEMORY PROBLEMS. OF THOSE SURVEYED, 60 PER CENT INDICATED IF THEY RECEIVED A DIAGNOSIS OF DEMENTIA THEY WOULD FEEL A SENSE OF SHAME; NEARLY HALF SAID THEY WOULD BE HUMILIATED BY A DIAGNOSIS OF DEMENTIA.

NO ONE IN THIS DAY AND AGE SHOULD HAVE A SENSE OF SHAME WHEN THEY RECEIVE A DIAGNOSIS OF DEMENTIA ANY MORE THAN THEY SHOULD WITH A DIAGNOSIS OF ANY OTHER CHRONIC DISEASE.

I WAS EXCITED TO READ TWO RECENTLY-RELEASED STUDIES IN THE UNITED KINGDOM AND DENMARK WHICH PROVIDE EVIDENCE THAT DEMENTIA, LIKE OTHER CHRONIC DISEASES, IS INFLUENCED BY SOCIAL AND LIFESTYLE FACTORS.

THESE PARTICULAR STUDIES CHALLENGE THE ASSUMPTION THAT PREVALENCE RATES OF DEMENTIA ARE CONSTANT ACROSS GENERATIONS AND THAT THE NUMBERS OF PEOPLE WITH DEMENTIA IS SIMPLY A FUNCTION OF THE NUMBER OF OLDER PEOPLE IN THE POPULATION.

BOTH STUDIES FOUND THAT FOR A GIVEN POPULATION COHORT, THE RISK OF DEVELOPING DEMENTIA MIGHT ACTUALLY GO DOWN.

IN ENGLAND AND WALES, DEMENTIA RATES OVER THE LAST TWO DECADES WERE SHOWN TO HAVE DROPPED BY 24% AMONG THOSE 65 AND OLDER.

AND IN DENMARK THE PERCENTAGE OF THOSE OVER 90 WHOSE COGNITIVE ABILITIES WERE SEVERELY IMPAIRED ALSO DROPPED BETWEEN 1998 AND 2010.

THE STUDIES REITERATE THE MESSAGE THAT DEMENTIA IS NOT AN INEVITABLE PART OF AGEING. IT IS A CHRONIC DISEASE.

THE COMPLEXITY OF THE ARGUMENT IS OF COURSE THAT ALTHOUGH THE RISK OF DEMENTIA FOR ANY POPULATION MAY DECLINE OVER TIME – AND EVEN THAT MAY BE UNCERTAIN – THE TOTAL NUMBER OF PEOPLE WITH DEMENTIA WILL CONTINUE TO RISE BECAUSE OF THE AGEING OF THE POPULATION.

THE POSITIVE NEWS IS THAT SUCCESSIVE GENERATIONS, OR EVEN SLIGHTLY YOUNGER GROUPS SEPARATED BY AS LITTLE AS TEN YEARS MIGHT NOT HAVE THE SAME RISK.

HOW WONDERFUL TO THINK OUR GRANDCHILDREN MIGHT BE LESS LIKELY TO DEVELOP DEMENTIA THAN WE ARE.

IN THEIR INTERPRETATION OF THEIR STUDY, THE AUTHORS SAY: “THE SCALE OF REDUCTION WE HAVE IDENTIFIED IS SUBSTANTIAL AND IS IN LINE WITH MAJOR REDUCTIONS IN RISK FACTORS IN HIGHER INCOME COUNTRIES, WHICH HAVE BEEN MODIFIED BY SOCIETAL CHANGES SUCH AS IMPROVEMENTS IN EDUCATION AND PREVENTION AND TREATMENT STRATEGIES IN RECENT DECADES.”

THEY GO ON TO MAKE AN OBSERVATION WHICH IS OF ENORMOUS INTEREST TO ALL OF US AT ALZHEIMER’S AUSTRALIA THAT “ALTHOUGH MAJOR FACTORS COULD HAVE INCREASED DEMENTIA PREVALENCE AT SPECIFIC AGES – SUCH AS THOSE ASSOCIATED WITH DIABETES, SURVIVAL AFTER STROKES AND VASCULAR INCIDENTS – OTHER FACTORS THAT COULD DECREASE PREVALENCE SUCH AS IMPROVED PREVENTION OF VASCULAR MORBIDITY AND HIGHER LEVELS OF EDUCATION SEEM TO HAVE HAD A GREAT EFFECT”.

THE SIGNIFICANCE OF THESE REPORTS IS THAT THEY ENCOURAGE US TO RENEW OUR EFFORTS TO BETTER INFORM PEOPLE ON HOW THEY MAY BE ABLE TO REDUCE THEIR RISK OF DEVELOPING SOME OF THE MOST DEVASTATING DISEASES.

THE MESSAGE OF ADOPTING A HEALTHY LIFESTYLE IS AN IMPORTANT ONE AND IT'S A MESSAGE THAT BECOMES MUCH MORE POWERFUL WHEN WE CAN TELL PEOPLE THAT BY ADOPTING HEALTHY LIFESTYLES THEY MAY BE ABLE TO REDUCE THEIR RISK OF DEVELOPING NOT JUST DEMENTIA, BUT DIABETES, HEART DISEASE AND CANCER.

WE KNOW OF COURSE THAT SADLY SOME PEOPLE WILL DO ALL THE RIGHT THINGS; LIVE A HEALTHY LIFESTYLE AND BE SOCIALLY AND MENTALLY ACTIVE BUT STILL GET A DIAGNOSIS OF DEMENTIA.

WE DON'T WANT TO BLAME ANYONE FOR GETTING DEMENTIA... BUT WE DO HAVE A DUTY TO ENCOURAGE AUSTRALIANS TO PURSUE HEALTHIER LIFESTYLES.

BUT THE FACT IS THE MAJORITY OF AUSTRALIANS DON'T UNDERSTAND THE CONNECTION BETWEEN DEMENTIA AND OTHER CHRONIC DISEASES – SUCH AS DIABETES, HEART DISEASE AND STROKE.

NOR DO THEY UNDERSTAND THE CONNECTIONS BETWEEN A HEALTHY LIFESTYLE AND A HEALTHY BRAIN AND WHAT THEY CAN DO TO MAXIMISE THEIR BRAIN HEALTH.

OUR AIM IS TO REPEAT THESE MESSAGES UNTIL EVERY AUSTRALIAN ABSORBS THEM AND TAKES RESPONSIBILITY FOR THEIR BRAIN HEALTH.

AUSTRALIA IS FORTUNATE TO HAVE THE WORLD'S FIRST PUBLICLY-FUNDED DEMENTIA RISK REDUCTION PROGRAM THROUGH ALZHEIMER'S AUSTRALIA'S – *YOUR BRAIN MATTERS: THE POWER OF PREVENTION.*

THE PROGRAM IS EVIDENCE BASED AND PROPOSES FIVE SIMPLE STEPS TO MAXIMISE BRAIN HEALTH.

STEP 1: LOOK AFTER YOUR HEART. MANY PEOPLE ARE UNAWARE OF THE CONNECTION OF HEART HEALTH AND BRAIN HEALTH. RESEARCH INDICATES THAT CONDITIONS THAT AFFECT THE BLOOD VESSELS, PARTICULARLY WHEN THEY HAPPEN IN MID LIFE AFFECT BRAIN FUNCTION AND THINKING SKILLS. THIS INCLUDES HIGH BLOOD PRESSURE, HIGH CHOLESTEROL, TYPE TWO DIABETES AND OBESITY.

STEP 2: DO SOME KIND OF PHYSICAL ACTIVITY. NOW, MORE THAN EVER, THERE IS STRONG EVIDENCE THAT REGULAR PHYSICAL ACTIVITY IS ASSOCIATED WITH BETTER BRAIN FUNCTION AND REDUCED RISK OF COGNITIVE DECLINE AND DEMENTIA.

PHYSICAL ACTIVITY INCREASES BLOOD FLOW TO THE BRAIN, STIMULATES THE GROWTH OF BRAIN CELLS AND THE CONNECTIONS BETWEEN THOSE BRAIN CELLS, AND IS ASSOCIATED WITH LARGER BRAIN VOLUME. IT ALSO REDUCES THE RISK OF HIGH BLOOD PRESSURE, HIGH CHOLESTEROL, DIABETES AND OBESITY.

RECENTLY ALZHEIMER'S AUSTRALIA LAUNCHED AN EVIDENCE BASED PAPER IN PARTNERSHIP WITH FITNESS AUSTRALIA. IT REPORTS ON A RANGE OF INTERNATIONAL AND LOCAL STUDIES THAT EXAMINES THE LINK BETWEEN PHYSICAL ACTIVITY, BRAIN HEALTH AND DEMENTIA RISK.

THE PAPER REFERS TO A RECENT STUDY THAT ESTIMATED A 25 PER CENT REDUCTION IN PHYSICAL INACTIVITY RATES COULD POTENTIALLY PREVENT NEARLY ONE MILLION CASES OF ALZHEIMER'S DISEASE WORLD WIDE.

ANOTHER STUDY SHOWED THAT IF EVERY FIVE YEARS, FIVE PER CENT OF INACTIVE PEOPLE BECAME ACTIVE, THIS WOULD REDUCE DEMENTIA PREVALENCE IN AUSTRALIA BY 11 PER CENT BY 2051. THAT EQUATES TO ABOUT 100,000 FEWER AUSTRALIANS LIVING WITH DEMENTIA.

STEP 3: MENTALLY CHALLENGE YOUR BRAIN. THE KEY TO MENTALLY CHALLENGING YOUR BRAIN IS TO CONTINUE TO LEARN NEW THINGS THROUGHOUT LIFE. PICK UP NEW HOBBIES, MAKE NEW DISCOVERIES, TRAVEL, EXPLORE OR ENROL IN A COURSE.

STAYING IN THE WORKFORCE CAN ALSO BE BENEFICIAL FOR THE BRAIN. I TOOK GREAT SATISFACTION FROM A RECENT REPORT FROM FRANCE THAT FOUND DELAYING RETIREMENT WAS ASSOCIATED WITH LOWERING A PERSON'S RISK OF DEMENTIA.

I HADN'T PLANNED ON STOPPING ANY TIME SOON, BUT IT IS REASSURING TO GET AFFIRMATION THAT BEING MENTALLY ACTIVE DOESN'T HAVE TO STOP WHEN YOU REACH A PARTICULAR AGE.

STEP 4: FOLLOW A HEALTHY DIET. DIETS LOW IN SATURATED FATS AND HIGH IN VEGETABLES AND FRUITS ARE ASSOCIATED WITH BETTER BRAIN FUNCTION AND REDUCED DEMENTIA RISK. BUT WE DO NEED FURTHER RESEARCH TO UNDERSTAND IF THERE ARE SPECIFIC FOODS THAT MAY REDUCE THE RISK OF DEMENTIA.

STEP 5: ENJOY SOCIAL ACTIVITY. MOST OF US ARE SOCIAL BEINGS AND USUALLY PREFER THE COMPANY OF OTHERS. IT IS ALWAYS MUCH MORE FUN DOING THINGS WITH OTHER PEOPLE, IT MAKES EXPERIENCES OF GOING TO THE MOVIES, CONCERTS, DANCING, TRAVELLING OR EVEN DISCOVERING A NEW RESTAURANT MORE ENJOYABLE.

RESEARCH SUGGESTS THAT SOCIAL ACTIVITIES THAT ALSO INVOLVE MENTAL STIMULATION AND PHYSICAL ACTIVITY CAN PROVIDE EVEN GREATER BENEFIT.

CHANGING ATTITUDES TO DEMENTIA THROUGH *YOUR BRAIN MATTERS* IS IMPORTANT BUT WE HAVE TO GO MUCH FURTHER IF WE ARE TO PROMOTE A BETTER UNDERSTANDING OF DEMENTIA.

IN THE PRESENT ECONOMIC CLIMATE, THE TIME IS LONG PAST FOR GOVERNMENT FUNDING OF EXPENSIVE AWARENESS CAMPAIGNS – AS MUCH AS I BELIEVE THEY CAN SERVE AN EXTREMELY USEFUL PURPOSE AS THEY DID WITH OUR HIV/AIDS AWARENESS PROGRAMS.

NO AMOUNT OF GOVERNMENT FUNDING OR INCREASED NUMBERS OF CARE PACKAGES WILL MAKE OLDER PEOPLE IN OUR SOCIETY FEEL VALUED. IT IS THE RESPONSIBILITY OF ALL OF US TO ENGAGE OLDER PEOPLE IN OUR COMMUNITIES TO STAND UP FOR THEIR RIGHTS AND REFUSE TO ACCEPT AGEISM.

I BELIEVE IT'S TIME FOR ALL AUSTRALIANS TO ENGAGE WITH DEMENTIA IF THEY ARE TO BETTER COMPREHEND WHAT A DIAGNOSIS MEANS FOR THE PERSON AND THEIR FAMILIES. ONLY IN THIS WAY WILL PEOPLE BE ABLE TO UNDERSTAND WHAT THEY CAN DO TO HELP THOSE WITH DEMENTIA FEEL LESS ISOLATED AND STIGMATISED.

EARLIER THIS YEAR ALZHEIMER'S AUSTRALIA PRODUCED TWO PUBLICATIONS: *DEMENTIA- FRIENDLY SOCIETIES* AND *CREATING DEMENTIA- FRIENDLY ORGANISATIONS* THAT ADDRESS THE NEED FOR SOCIAL INCLUSION.

BOTH THESE INITIATIVES ARE ABOUT ENGAGING WITH PEOPLE WITHIN OUR COMMUNITIES WHO HAVE DEMENTIA; ABOUT TREATING PEOPLE EQUALLY AND WITH RESPECT REGARDLESS OF THEIR AGE, GENDER OR DISABILITIES.

CHOIRS, WALKING GROUPS AND MEMORY CAFES ARE PROJECTS THAT ALZHEIMER'S AUSTRALIA IS ALREADY IMPLEMENTING TO ENCOURAGE COMMUNITIES TO BECOME DEMENTIA FRIENDLY.

CONSUMERS HAVE BEEN ASKING FOR A COGNITIVE IMPAIRMENT SYMBOL FOR SOME TIME. THE OBJECTIVE OF THE SYMBOL IS TO GET ORGANISATIONS SUCH AS BANKS, RETAILERS AND CENTRELINK TO AGREE TO MAKE A COMMITMENT TO TRAIN AND EDUCATE STAFF ABOUT DEMENTIA AND ON THE BEST WAY TO COMMUNICATE WITH SOMEONE WHO HAS COGNITIVE IMPAIRMENT.

I'M DELIGHTED TO TELL YOU THE ANZ HAS ALREADY SIGNED UP TO INCORPORATE TRAINING ON DEMENTIA INTO THEIR STAFF DEVELOPMENT PROGRAM. IN NSW DEMENTIA TRAINING IS BEING ROLLED OUT TO ALL TRANSPORT WORKERS, AND I TRUST IT WON'T BE LONG UNTIL OTHER MAJOR SERVICE PROVIDERS FOLLOW.

IN VICTORIA A COGNITIVE IMPAIRMENT SYMBOL IS BEING USED IN 22 HOSPITALS WITH THE PERMISSION OF THE PATIENT AND THEIR FAMILY TO DENOTE A PATIENT WITH DEMENTIA.

A PATIENT WITH COGNITIVE IMPAIRMENT MAY BE SUBJECT TO THE RISK OF FALLS, MALNUTRITION OR DELUSIONS – THE SYMBOL HELPS MAKE HOSPITALS SAFER.

ALZHEIMER'S AUSTRALIA HAS PRODUCED A SERIES OF DVDS CALLED *IS IT DEMENTIA?* DESIGNED TO ASSIST SERVICE PROVIDERS AS DIVERSE AS BANKING, RETAIL, PUBLIC TRANSPORT, EMERGENCY SERVICES, CORRECTIONAL SERVICES AND THE GENERAL COMMUNITY TO BETTER UNDERSTAND DEMENTIA AND HOW TO COMMUNICATE WITH PEOPLE WITH DEMENTIA IN A WAY THAT GIVES THEM RESPECT AND DIGNITY.

AN ENDURING AND VITAL ASPECT OF THE FIGHT DEMENTIA CAMPAIGN WILL BE IMPROVED ACCESS TO QUALITY DEMENTIA CARE SERVICES.

THE FEDERAL GOVERNMENT'S *LIVING LONGER. LIVING BETTER.* AGED CARE REFORMS PROVIDE A POSITIVE FRAMEWORK FOR CARRYING THIS FORWARD – PARTICULARLY THE EXPANSION OF COMMUNITY CARE PACKAGES FROM 64,800 TO 144,469 IN THE NEXT 10 YEARS.

THIS PAIRED WITH THE INTRODUCTION OF CONSUMER DIRECTED CARE WILL MAKE THE CONSUMER AN EQUAL PARTNER WITH THE SERVICE PROVIDER IN DECISION MAKING ABOUT WHAT SERVICES ARE NEEDED TO RESPOND TO THEIR PARTICULAR NEEDS.

IN THIS WAY THERE IS THE PROSPECT OF ENABLING PEOPLE TO HAVE ACCESS TO THE MORE FLEXIBLE SERVICES THEY NEED IF THEY ARE TO ACHIEVE THE POLICY OBJECTIVE OF STAYING AT HOME LONGER.

WHILE WE SEEM TO BE ON THE RIGHT TRACK I AM REMINDED BY THE STORIES OF CONSUMERS THAT WE HAVE A LONG WAY TO GO.

SOME OF THE MOST DIFFICULT STORIES I HAVE HEARD FROM CONSUMERS IS ABOUT THE QUALITY OF CARE AT END OF LIFE; OF PEOPLE BEING TOLD THEY CAN'T ACCESS PALLIATIVE CARE SERVICES BECAUSE THEY ARE NOT DYING QUICKLY ENOUGH.

PEOPLE MAY DIE IN INCREDIBLE PAIN, BECAUSE THE MANAGEMENT OF THE FACILITY IS CONCERNED THAT THE USE OF MORPHINE MAY HASTEN THE PERSON'S DEATH.

FOR PEOPLE WITH DEMENTIA AND THEIR FAMILIES, THE ISSUES AROUND END OF LIFE ARE COMPLEX. THE PERSON HAS USUALLY LOST THE CAPACITY TO BE INVOLVED IN THE CARE DECISIONS AT END OF LIFE AND THIS MAKES ADVANCED CARE PLANNING ALL THE MORE CRITICAL. YET WE KNOW MOST PEOPLE WITH DEMENTIA HAVE NOT DOCUMENTED THEIR CARE WISHES.

AGED CARE PROVIDERS SHOULD BE ENCOURAGING PEOPLE TO DOCUMENT THEIR WISHES WHEN THEY ENTER CARE. HOW CAN A SERVICE PROVIDER PROVIDE QUALITY CARE FOR A PERSON IF THEY DON'T KNOW WHAT THE PERSON WANTS?

ISSUES AROUND QUALITY GO BEYOND JUST THE CARE AT THE END OF SOMEONE'S LIFE. IN THE LAST 12 MONTHS THERE HAVE BEEN SEVEN *LATELINE* REPORTS ILLUSTRATING SOME EXTREMELY DISTURBING SITUATIONS INVOLVING POOR CARE IN RESIDENTIAL FACILITIES.

I AM SURE WE ALL AGREE THERE SHOULD BE ZERO TOLERANCE FOR POOR CARE THAT FAILS TO RESPECT THE DIGNITY OF THE OLDER PERSON AND DENIES THEIR HUMAN RIGHTS.

WE'RE NOT GOING TO GET ACHIEVE BETTER QUALITY OF CARE UNLESS PROVIDERS, CONSUMERS, UNIONS AND PROFESSIONAL ORGANISATIONS GET TOGETHER WITH GOVERNMENT TO CONSIDER THE STRATEGIES NEEDED TO ACHIEVE THAT RESULT.

WE ARE YET TO UNDERSTAND WHY IT IS THAT SOME SERVICE PROVIDERS DO AN EXCELLENT JOB WITH THEIR EXISTING FUNDING, EVEN THOUGH IT IS CONSTRAINED, WHILE OTHERS STRUGGLE. GOOD CARE INVOLVES MORE THAN FUNDING.

THIS WILL REQUIRE URGENT CHANGES TO THE WAY COMPLAINTS ARE HANDLED. COMPLAINTS RELATED TO MEDICATION, ASSAULTS AND PHYSICAL RESTRAINTS NEED TO BE HANDLED QUICKLY AND GOVERNMENT GUIDELINES ON THE USE OF PSYCHOTROPIC MEDICATION AND RESTRAINTS MUST BE STRICTLY RESERVED.

AN INDEPENDENT COST OF CARE STUDY IN RESIDENTIAL CARE NEEDS TO BE DONE TO ENSURE FUNDING IS ADEQUATE FOR THE PROVISION OF HIGH QUALITY CARE.

AND WE NEED TO LOOK FOR INDUSTRY LEADERSHIP AND CONSUMER INVOLVEMENT THAT RESULTS IN THE CULTURAL CHANGE AND TRAINING NECESSARY TO ACHIEVE RESPECT OF PERSON CENTRED CARE.

MOST IMPORTANTLY AUSTRALIA NEEDS REGULATORY ACTION TO ADDRESS THE OVER PRESCRIPTION OF ANTI-PSYCHOTIC MEDICATIONS, FOR EXAMPLE, PUBLIC REPORTING ON THE USE OF MEDICATIONS AND PHYSICAL RESTRAINTS ON THE MYAGE WEBSITE.

THERE HAS TO BE GREATER TRANSPARENCY FOR THE CONSUMER IN THE CARE OUTCOMES BEING ACHIEVED, BECAUSE THE CURRENT STANDARDS AND ACCREDITATION SYSTEM IS FAILING TO TELL CONSUMERS WHAT THEY NEED TO KNOW.

AS I SAID AT THE OUTSET WE ARE IN THE PROCESS OF DEVELOPING OUR FUTURE VISION TO PRESENT TO THE NEW GOVERNMENT.

CENTRAL TO THIS NEW CAMPAIGN WILL BE SOME OF THE ISSUES I HAVE TOUCHED ON IN THIS TALK INCLUDING:

- **PROMOTING A BETTER UNDERSTANDING OF DEMENTIA THROUGH *YOUR BRAIN MATTERS* AND THROUGH ACTIVE COMMUNICATION OF THE OUTCOMES OF RESEARCH.**
- **SUPPORTING APPROACHES THAT ASSIST THE SOCIAL INCLUSION OF ALL OLDER PEOPLE INCLUDING THOSE WITH DEMENTIA THROUGH INITIATIVES SUCH AS AGE FRIENDLY AND DEMENTIA-FRIENDLY COMMUNITIES AND ORGANISATIONS.**
- **ENSURING THAT THE FOCUS ON EXPANDING COMMUNITY CARE AND THE EMPOWERMENT OF CONSUMERS THROUGH CONSUMER DIRECTED CARE IS CONTINUED IN THE IMPLEMENTATION OF THE AGED CARE REFORMS.**
- **IMPLEMENTING STRATEGIES THAT IMPROVE THE QUALITY OF DEMENTIA CARE IN RESIDENTIAL CARE SERVICES.**

IF WE DON'T ENGAGE PEOPLE WITH DEMENTIA IN OUR COMMUNITIES AND PROVIDE THEM WITH ACCESS TO SERVICES THAT MANY OF US TAKE FOR GRANTED, WE WILL SIMPLY PUT THEM AT THE BACK OF THE QUEUE.

THIS IS UNACCEPTABLE AND JUST NOT GOOD ENOUGH BUT ENGAGING PEOPLE WITH DEMENTIA ISN'T SOMETHING THAT WILL BE ACHIEVED UNLESS WE ALL WORK TOGETHER.

I AM INCREASINGLY HOPEFUL MORE AUSTRALIANS WILL SHARE MY VIEW AND I HOPE ALL OF YOU IN THIS ROOM DO SO TOO.

THANK YOU.