

THE NEED FOR PALLIATIVE CARE

**PALLIATIVE CARE AUSTRALIA CONFERENCE
NATIONAL CONVENTION CENTRE
CANBERRA**

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A LOT HAS HAPPENED SINCE PROFESSOR IAN MADDOCKS AND I LAST SHARED THE STAGE IN CANBERRA EARLIER THIS YEAR. IT WAS A MOMENT IN TIME THAT CHANGED BOTH OUR LIVES.

AS I'VE GOT TO KNOW HIM A LITTLE AND LEARN MORE ABOUT HIS WORK I APPRECIATE WHAT A WORTHY RECIPIENT OF SENIOR AUSTRALIAN OF THE YEAR HE IS. NOT LONG AGO IAN SENT ME A MESSAGE SAYING THAT MAGGIE BEER, A FORMER SENIOR AUSTRALIAN OF THE YEAR, WARNED HIM HIS WORLD WOULD BE TURNED UPSIDE DOWN.

“SHE’S RIGHT,” IAN SAID. “IT IS. HOW’S YOUR WORLD?” HE ASKED.

“UPSIDE DOWN”, I REPLIED.

I AM TRULY DELIGHTED TO HAVE THE OPPORTUNITY TO SHARE THIS PARTICULAR PLATFORM AT THIS IMPORTANT CONFERENCE WITH HIM TODAY.

I AM ALSO PLEASED TO HAVE THE OPPORTUNITY TO SPEAK TO YOU ALL TODAY.

HOW LUCKY AUSTRALIA IS TO HAVE SO MANY ADVOCATES AND HEALTH CARE PROFESSIONALS WHO ARE ALL WORKING TO IMPROVE END OF LIFE CARE.

WE HAVE SOMETHING IN COMMON THAT PROBABLY WE WISH WE DIDN'T...GETTING PEOPLE TO TALK ABOUT ISSUES IN DEMENTIA CARE AND AT END OF LIFE.

DEPRESSINGLY AGED CARE AND END OF LIFE ISSUES HAVE RECEIVED LITTLE ATTENTION IN THE CURRENT ELECTION CAMPAIGN.

POLITICIANS AND THE WIDER COMMUNITY FIND IT DIFFICULT TO TALK ABOUT DEATH ALTHOUGH IT IS SOMETHING THAT WE WILL ALL FACE ONE DAY. IT REMAINS A TOPIC MOST PEOPLE DO THEIR BEST TO AVOID.

IN MAY THIS YEAR, PALLIATIVE CARE AUSTRALIA COMMISSIONED A SURVEY OF AUSTRALIANS WHO HAD RECENTLY LOST A LOVED ONE. IT FOUND THAT HALF HAD NOT DISCUSSED THEIR END OF LIFE CARE.

ONLY 15 PER CENT OF THOSE WHO DIED HAD AN ADVANCE CARE PLAN IN PLACE WHICH DETAILED THEIR WISHES, AND ALMOST ONE IN THREE OF THOSE SURVEYED WEREN'T CARED FOR IN THE PLACE OF THEIR CHOICE.

ANOTHER PALLIATIVE CARE AUSTRALIA SURVEY IN 2011, FOUND THAT ONLY AROUND A THIRD OF PEOPLE HAD DISCUSSED THEIR WISHES ABOUT THEIR END OF LIFE CARE WITH THEIR LOVED ONES.

I THINK MANY PEOPLE PRESUME THAT THE PEOPLE WHO CARE ABOUT THEM WILL KNOW WHAT THEY WANT WHEN THEY DIE. HOWEVER RESEARCH SUGGESTS WE REALLY AREN'T ALL THAT GOOD AT GUESSING WHAT THE WISHES OF THE PEOPLE WE LOVE MIGHT BE.

RESEARCH ON THE ACCURACY OF SUBSTITUTE DECISION MAKING FOUND THAT DECISION MAKERS SELECTED BY THE PERSON NEARING THE END OF THEIR LIFE PREDICTED TREATMENT PREFERENCES WITH 68 PER CENT ACCURACY, WHICH MEANS IN A THIRD OF CASES THEY GOT IT WRONG.

OTHER STUDIES HAVE FOUND THAT NEXT OF KIN PERFORM AT ABOUT “CHANCE” LEVELS WHEN PREDICTING THE END OF LIFE PREFERENCES OF THE PERSON THEY CARE ABOUT.

JUST THINK. THAT MEANS A SPOUSE OR A CHILD MIGHT AS WELL FLIP A COIN AS TRY TO ANTICIPATE WHAT WISHES THEIR LOVED ONE MIGHT HAVE AT THE END OF THEIR LIFE.

FOR ME, THERE SURELY IS NO BETTER ARGUMENT THAN THAT FOR DOCUMENTING OUR WISHES EARLY AND REVIEWING THEM OFTEN.

THIS IS ALL THE MORE IMPORTANT FOR PEOPLE WITH DEMENTIA , SINCE AT SOME POINT IN THE DISEASE IT IS LIKELY THAT A PERSON WITH THE DISEASE WILL LOSE THE CAPACITY TO PARTICIPATE IN DECISION MAKING ABOUT THEIR END OF LIFE CARE.

I WANT TO CONCENTRATE ON TWO IMPORTANT ISSUES IN MY TALK TODAY...

- END OF LIFE CARE AND THE SPECIAL CHALLENGES FACED BY PEOPLE WITH DEMENTIA.

- **THE CHALLENGES IN GETTING TRACTION ON DIFFICULT SOCIAL ISSUES AND HOW THE STORIES OF PEOPLE EXPERIENCING THESE ISSUES CAN BE HARNESSSED TO TACKLE STIGMA.**

WHEN ALZHEIMER'S AUSTRALIA CONDUCTED ITS NATIONAL CONSULTATIONS WITH PEOPLE WITH DEMENTIA AND THEIR FAMILIES ON THE AGED CARE REFORMS, SOME OF THE MOST MOVING STORIES WERE ABOUT END OF LIFE CARE.

THE PAIN AND LINGERING GUILT THAT FAMILIES FELT WHEN THEY WERE UNABLE TO ENSURE THAT THE WISHES OF THE PERSON WITH DEMENTIA WERE RESPECTED WAS OVERWHELMING.

FOR EXAMPLE ONE WOMAN TOLD IS: *"I WAKE UP AT NIGHT THINKING ABOUT IT. MY MOTHER'S WISHES WERE NOT TAKEN NOTE OF... I HAD TO PLEA THAT MUM WOULD NOT BE TAKEN TO HOSPITAL IN AN AMBULANCE."*

END OF LIFE CARE FOR PEOPLE WITH DEMENTIA DIFFERS IN IMPORTANT RESPECTS FROM OTHER TERMINAL CONDITIONS.

DEMENTIA IS A LONG AND UNPREDICTABLE DISEASE. THIS CAN MEAN IT IS HARD TO KNOW WHEN 'END OF LIFE' CARE SHOULD BEGIN. THERE IS ALSO A LACK OF COMMUNITY UNDERSTANDING ABOUT DEMENTIA. IN RESEARCH COMMISSIONED BY ALZHEIMER'S AUSTRALIA IN 2011, ONLY 20 PER CENT OF PEOPLE CORRECTLY INDICATED THAT ALZHEIMER'S DISEASE WAS A TERMINAL ILLNESS.

AS A RESULT PEOPLE WITH DEMENTIA HAVE DIFFICULTY GETTING ACCESS TO PALLIATIVE CARE SERVICES. ONE CARER TOLD US: *"I'VE BEEN TOLD THAT IF MY MOTHER DOES NOT DIE FAST ENOUGH IN A PALLIATIVE CARE SETTING SHE WILL BE SENT AWAY. I AM FIGHTING FOR MY MOTHER TO DIE IN A PALLIATIVE FACILITY BECAUSE I AM TOLD SHE IS NOT WORTHY."*

THE DIFFICULT ISSUES AROUND CAPACITY COMPLICATE END OF LIFE CARE AS WELL. PEOPLE WITH DEMENTIA SHOULD BE ENCOURAGED TO DOCUMENT THEIR WISHES EARLY IN THEIR DISEASE, BUT THIS OFTEN DOESN'T HAPPEN. SO FAMILY MEMBERS ARE LEFT UNCERTAIN, HAVING TO GUESS WHAT THE PERSON WITH DEMENTIA WOULD HAVE WANTED.

AND AS I SAID EARLIER, WE ARE JUST NOT ALL THAT GOOD AT ANTICIPATING EXACTLY WHAT THAT IS.

I AM PLEASED TO BE LAUNCHING A JOINT POSITION STATEMENT TODAY. ON PALLIATIVE CARE AND DEMENTIA, DEVELOPED BY ALZHEIMER'S AUSTRALIA AND PALLIATIVE CARE AUSTRALIA.

IT WILL BE AN IMPORTANT TOOL FOR BOTH OUR ORGANISATIONS IN RAISING AWARENESS ABOUT KEY ISSUES AROUND PALLIATIVE CARE AND DEMENTIA.

THIS DOESN'T MEAN WE HAVE ALL THE ANSWERS THOUGH. PERHAPS BECAUSE DEMENTIA IS SO DIFFERENT FROM OTHER DISEASES, WE STRUGGLE WITH WHAT TERMINOLOGY TO USE AND HOW TO DESCRIBE THE SUPPORTIVE APPROACH TO CARE THAT WE WANT FOR PEOPLE WITH DEMENTIA.

EARLIER THIS YEAR, ALZHEIMER'S AUSTRALIA INVITED A BRITISH EXPERT IN DEMENTIA CARE, PROFESSOR JULIAN HUGHES TO CONDUCT A SPEAKING TOUR OF AUSTRALIA. HE ALSO DEVELOPED AN EXCELLENT PAPER FOR US "MODELS OF DEMENTIA CARE: PERSON CENTRED, PALLIATIVE AND SUPPORTIVE", WHICH WORKED THROUGH SOME OF THESE HARD ISSUES.

PROFESSOR HUGHES TALKED ABOUT A NEW WAY OF CONCEPTUALISING CARE FOR PEOPLE WITH DEMENTIA; HE REFERS TO IT AS SUPPORTIVE CARE.

IT'S AN APPROACH THAT HAS LESS OF AN EMPHASIS ON DEATH AND RELATES TO THE CARE PROVIDED FROM THE POINT OF DIAGNOSIS TO DEATH.

WHAT WAS MOST REASSURING ABOUT PROFESSOR HUGHES' TALKS WAS HOW WELL THIS IDEA OF SUPPORTIVE CARE RESONATED WITH CONSUMERS. PERHAPS IT COMES DOWN TO THE FACT THAT NO MODEL OF CARE WILL WORK FOR EVERYONE.

WHAT WE NEED IS A PHILOSOPHY OF CARE THAT'S SENSIBLE AND FOR CLINICIANS AND HEALTH PROFESSIONALS TO APPLY THIS KIND OF APPROACH TO CARE SO AS TO MEET THE INDIVIDUAL NEEDS OF PEOPLE.

IT IS RARE THAT ONE APPROACH WORKS FOR EVERYONE. PEOPLE WITH DEMENTIA ARE NOT ALL THE SAME. THE DISEASE MAY AFFECT DIFFERENT PARTS OF THE BRAIN CAUSING DIFFERENT SYMPTOMS AND DISEASE PROGRESSION.

BUT WHAT IS OF UTMOST IMPORTANCE IS THE FACT THAT DEMENTIA IS A DISEASE WHICH AFFECTS UNIQUE HUMAN BEINGS. EACH PERSON HAS DIFFERENT GOALS, PERSONALITIES, AND PREFERENCES.

I'M EXCITED ABOUT THE WORK OF JULIAN HUGHES AND ALSO THE WORK THAT WE'VE DONE FOR THIS JOINT POSITION STATEMENT BECAUSE IT BEGINS TO OUTLINE THE PRINCIPLES THAT WE BELIEVE IN RATHER THAN DEVELOPING SPECIFIC MODELS OF CARE SUCH AS RECOGNISING THAT:

- PEOPLE WITH DEMENTIA HAVE THE RIGHT TO DIE PEACEFULLY, WITH DIGNITY AND IN A WAY THAT RESPECTS THEIR WISHES.**
- THERE IS A NEED FOR AN HOLISTIC AND SUPPORTIVE APPROACH TO CARE.**
- PEOPLE SHOULD BE ENCOURAGED TO DOCUMENT THEIR WISHES EARLY IN THE DISEASE BEFORE THEY BEGIN TO LOSE CAPACITY.**
- PALLIATIVE AND SUPPORTIVE CARE SHOULD BE AVAILABLE WHERE AND WHEN PEOPLE NEED IT.**

- **NO ONE SHOULD BE TURNED AWAY FROM PALLIATIVE CARE SERVICES BECAUSE OF THEIR DIAGNOSIS OF DEMENTIA.**

TO ME THESE ARE SIMPLE AND OBVIOUS STATEMENTS, BUT WHEN I LISTEN TO THE STORIES OF CONSUMERS, IT'S CLEAR THAT THESE SIMPLE PRINCIPLES ARE NOT BEING APPLIED IN SO MANY CASES...TOO MANY.

IT'S NOT AN INSIGNIFICANT MATTER. LACK OF APPROPRIATE END OF LIFE CARE LEADS TO SUFFERING IN THE LAST MOMENTS OF LIFE FOR THE PERSON WITH DEMENTIA. IT ALSO CAN LEAD TO A LIFETIME OF GUILT AND PAIN FOR THEIR FAMILY.

I AM PLEASED THAT WE'VE BEEN ABLE TO WORK TOGETHER ON THIS STATEMENT WHICH IS AVAILABLE AT THE LITERATURE DESK IN THE FOYER.

IN THE LAST FEW YEARS, THERE HAS BEEN A NUMBER OF SIGNIFICANT INITIATIVES THAT I THINK PALLIATIVE CARE AUSTRALIA AND OTHER ADVOCATES FOR PALLIATIVE CARE CAN BE RIGHTLY PROUD.

THE SENATE INQUIRY IN 2012 WAS IMPORTANT IN HIGHLIGHTING ISSUES AROUND PALLIATIVE CARE SERVICES AND MAKING NUMEROUS RECOMMENDATIONS ON HOW TO IMPROVE THE SYSTEM.

THE *LIVING LONGER. LIVING BETTER* AGED CARE REFORMS PASSED BY PARLIAMENT EARLIER THIS YEAR INCLUDES \$21.7 MILLION TO SUPPORT BETTER PALLIATIVE CARE AND SUPPORT IN THE AGED CARE SYSTEM.

ALZHEIMER'S AUSTRALIA HAS BEEN PLAYING ITS PART, TOO. SINCE 2005, WE'VE PUT OUT SEVEN PUBLICATIONS ON ADVANCE CARE PLANNING AND PALLIATIVE CARE. THESE PUBLICATIONS HAVE INCLUDED ONE ON EUTHANASIA, NOT TO STATE A POSITION, BUT TO HELP THE WIDER COMMUNITY UNDERSTAND THE ISSUES INVOLVED.

WE ARE DEEPLY GRATEFUL TO PROFESSOR COLLEEN CARTWRIGHT, NOT ONLY FOR THAT PARTICULAR PUBLICATION, BUT FOR HER ENERGY AND SUPPORT IN CONDUCTING SEMINARS AROUND AUSTRALIA ON THE IMPORTANCE OF ADVANCE PLANNING AND END OF LIFE ISSUES.

WE ARE ALSO VERY THANKFUL FOR THE SUPPORT OF THE BUPA HEALTH FOUNDATION, WITHOUT WHICH THESE RECENT PUBLICATIONS AND SEMINARS WOULD NOT HAVE BEEN POSSIBLE.

AS PART OF ALZHEIMER'S AUSTRALIA'S KNOWLEDGE TRANSLATION ACTIVITIES THROUGH THE NATIONAL DEMENTIA QUALITY INITIATIVE, WE HAVE COMMITTED MORE THAN \$600,000 TO TWO PROGRAMS THAT ARE SYSTEMATICALLY TURNING THE BEST AVAILABLE EVIDENCE ON PALLIATIVE CARE AND ADVANCE CARE PLANNING INTO BETTER DEMENTIA CARE SERVICES AND SUPPORT THROUGHOUT AUSTRALIA.

THE FIRST OF THESE IS THE 'INTEGRATED CARE FRAMEWORK – DEMENTIA PROJECT, LED BY HAMMONDCARE IN PARTNERSHIP WITH KEY STAKEHOLDERS INCLUDING PALLIATIVE CARE AUSTRALIA. THIS PROGRAM CONSISTS OF AN ONLINE, INTERACTIVE SUITE OF EVIDENCE-BASED EDUCATION MODULES, ASSESSMENT AND AUDIT TOOLS, AND AUDIO-VISUAL TEACHING MATERIALS ON END-OF-LIFE DEMENTIA CARE FOR USE IN RESIDENTIAL AGED CARE FACILITIES.

THIS RESOURCE IS CURRENTLY BEING REFINED IN NURSING HOMES IN THREE STATES AND TERRITORIES AND WHEN FINALISED, WILL BE PROMOTED WIDELY TO RESIDENTIAL AGED CARE PROVIDERS AROUND AUSTRALIA.

THIS PROJECT HAS ALSO BEEN ABLE TO DEVELOP A 'DEMENTIA FILTER' FOR THE NATIONAL 'CARE SEARCH' PALLIATIVE CARE KNOWLEDGE NETWORK THAT I'M SURE MANY OF YOU ARE FAMILIAR WITH.

THE SECOND PROJECT ON ADVANCE CARE PLANNING IS LED BY DR CHRIS SHANLEY FROM SYDNEY'S LIVERPOOL HOSPITAL, ALSO IN PARTNERSHIP WITH PALLIATIVE CARE AUSTRALIA.

IT IS BASED ON DR SHANLEY'S EXTENSIVE CONSULTATION WITH CONSUMERS, HEALTH PROFESSIONALS, GUARDIANSHIP AUTHORITIES AND STATE HEALTH OFFICIALS AROUND AUSTRALIA, AND HAS RESULTED IN A CONSUMER FRIENDLY AND TRULY NATIONAL SET OF RESOURCES THAT HELP PEOPLE ENGAGE WITH THEIR FAMILIES AND DOCTORS IN THE DISCUSSIONS NECESSARY TO PLAN AHEAD FOR END-OF-LIFE AND OTHER CONTINGENCIES.

THIS NEW RESOURCE CALLED 'START2TALK', WILL BE LAUNCHED AND PROMOTED WIDELY THROUGH SOCIAL MEDIA AND OTHER TRADITIONAL MEDIA OUTLETS LATER THIS YEAR.

AS VALUABLE AS THESE INITIATIVES ARE WE STILL NEED TO DO MORE. IN THE PUBLIC MINDSET THERE ENDURES A BARRIER TO THINKING OR TALKING ABOUT DEATH WHICH REQUIRES MORE DRAMATIC ACTION.

WE NEED TO ENGAGE THE PUBLIC AND ENSURE THAT DEATH IS NO LONGER A DIRTY, EMBARRASSING WORD. WE NEED PEOPLE TO FEEL COMFORTABLE TALKING ABOUT DEATH AND WHAT TYPE OF CARE THEY WANT AT THE END OF THEIR LIVES.

AS PRESIDENT OF ALZHEIMER'S AUSTRALIA, I'M ALL TOO AWARE OF HOW PEOPLE WANT TO TURN AWAY FROM AND AVOID DIFFICULT AND FRIGHTENING CONCEPTS. DEMENTIA IS ANOTHER 'D' WORD WHICH PEOPLE HAVE LONG TRIED TO AVOID TALKING ABOUT.

FOR PEOPLE WITH DEMENTIA, THE STIGMA ASSOCIATED WITH THE DISEASE IS INCREDIBLY HURTFUL. AFTER A DIAGNOSIS, PEOPLE OFTEN FACE NOT ONLY THEIR INTERNAL STRUGGLE WITH COMING TO TERMS WITH THE DISEASE, BUT ALSO A SUDDEN FEELING OF SOCIAL ISOLATION FRIENDS AND FAMILY MAY STOP CALLING OR COMING BY. OTHERS SUDDENLY BECOME QUIET WHEN THE DISEASE IS MENTIONED. SLOWLY BUT SURELY SOCIAL CONNECTIONS AND PARTICIPATION BEGINS TO WHITHER AWAY.

THE WORK WE'VE DONE THROUGH OUR FIGHT DEMENTIA CAMPAIGN, IN PARTICULAR THE POWER OF STORYTELLING, HAS RAISED PUBLIC AWARENESS ABOUT DEMENTIA IN A WAY THAT MANY THOUGHT WASN'T POSSIBLE.

WE HAVE FINALLY STOPPED BEING APOLOGETIC AND LEARNED TO HAVE A STRONG AND LOUD VOICE.

OUR FIGHT DEMENTIA CAMPAIGN WAS LAUNCHED IN OCTOBER 2011 WITH A MARCH OF 500 PEOPLE – PEOPLE WITH DEMENTIA, CARERS AND HEALTH PROFESSIONALS – ON THE LAWNS OF PARLIAMENT HOUSE, CANBERRA. IT WAS INSPIRATIONAL. SO MANY OF THOSE MARCHING SAID, “IT IS JUST SO WONDERFUL THAT AT LAST WE ARE DOING SOMETHING.”

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

NOT LONG AFTER, WE UNDERTOOK NATIONWIDE CONSULTATIONS ON THE AGED CARE REFORMS AND HEARD THE STORIES OF THOUSANDS OF PEOPLE LIVING WITH DEMENTIA AND THEIR FAMILIES.

WE WERE PLEASED TO REPORT THESE BACK TO GOVERNMENT AND TO UTILISE THEM TO RAISE AWARENESS ABOUT THE EXPERIENCES OF PEOPLE LIVING WITH THE DISEASE.

MOST RECENTLY, PEOPLE UNDER 65, LIVING WITH DEMENTIA, HAD THE OPPORTUNITY TO TALK ABOUT THEIR EXPERIENCES AT OUR YOUNGER ONSET DEMENTIA SUMMIT IN MELBOURNE.

ONCE AGAIN, MOVING STORIES WERE SHARED ABOUT WHAT IT MEANS TO LIVE WITH DEMENTIA AND THE SPECIAL ISSUES THAT YOUNGER PEOPLE FACE, INCLUDING THE IMPACT A DIAGNOSIS HAS ON CHILDREN AND THE FINANCIAL BURDEN CAUSED BY LOSS OF EMPLOYMENT.

PEOPLE LIVING WITH DEMENTIA ARE THE BACKBONE OF OUR FIGHT DEMENTIA CAMPAIGN AND THE REASON WHY IT HAS BEEN SO SUCCESSFUL IN COMMUNICATING THE IMPACT DEMENTIA HAS ON SO MANY AUSTRALIAN FAMILIES.

WE STILL HAVE A LONG WAY TO GO BUT I BELIEVE THAT PEOPLE ARE BEGINNING TO BE MORE OPEN ABOUT THEIR EXPERIENCES WITH DEMENTIA AND TO TALK ABOUT THE DISEASE.

WE'VE HAD GREAT SUCCESS IN GETTING ATTENTION THROUGH THE MEDIA WITH THESE EVENTS.

THE STORIES FROM THE YOUNGER ONSET DEMENTIA SUMMIT REACHED AN AUDIENCE OF MORE THAN 3.7 MILLION PEOPLE. OUR MARCH ON PARLIAMENT HOUSE REACHED AN AUDIENCE OF 7.6 MILLION.

THE RELEASE OF OUR AGED CARE CONSULTATIONS REPORT BROKE ALL OUR MEDIA RECORDS REACHING AN AUDIENCE OF 16 MILLION.

AND THAT'S JUST TRADITIONAL MEDIA. SOCIAL MEDIA HAS ENABLED PEOPLE TO COMMUNICATE THEIR STORIES IN A WAY THAT WE HAVE NEVER DONE BEFORE.

I THINK WE NEED TO BEGIN TO TACKLE DEATH AND DYING IN THE SAME WAY. WE NEED TO BEGIN SHARING OUR STORIES, BOTH THE GOOD AND BAD EXPERIENCES, AND TALKING MORE OPENLY ABOUT DEATH.

I APPLAUD YOUR CONFERENCE THEME – “PALLIATIVE CARE – EVERYONE’S BUSINESS”. I CHALLENGE YOU TO THINK CREATIVELY ABOUT HOW YOU CAN HARNESS THE STORIES AND EXPERIENCES OF YOUR CONSUMERS TO ENSURE THAT IT TRULY IS EVERYONE’S BUSINESS, AND THAT DEATH BECOMES A WORD THAT PEOPLE NO LONGER AVOID.

I WOULD BE REMISS IF I DID NOT ACKNOWLEDGE THE FEDERAL ELECTION. IT SEEMS OUR COUNTRY HAS BEEN ON EDGE FOR MONTHS BECAUSE OF THE POLITICAL UNCERTAINTY.

I LIVE IN HOPE THAT A NEW GOVERNMENT, FORMED FROM EITHER SIDE OF POLITICS, WILL PRESENT OPPORTUNITIES FOR BOTH PALLIATIVE CARE AND DEMENTIA.

THE *LIVING LONGER. LIVING BETTER* AGED CARE REFORMS INCLUDED IMPORTANT POLICY CHANGES AND FUNDING FOR BOTH CAUSES BUT IN ALZHEIMER'S AUSTRALIA'S VIEW THEY SIMPLY DON'T GO FAR ENOUGH.

WE ARE SEEKING A COMMITMENT FROM THE NEXT FEDERAL GOVERNMENT TO BUILD ON THE AGED CARE REFORMS BY:

- **INCREASING CHOICE AND FLEXIBILITY IN COMMUNITY CARE**
- **DEVELOPING DEMENTIA SPECIFIC RESPITE SERVICES**
- **IMPROVING THE QUALITY OF RESIDENTIAL AGED CARE**
- **DEVELOPING A NATIONAL NETWORK OF DEMENTIA KEY WORKERS TO SUPPORT PEOPLE WITH DEMENTIA OF ALL AGES**
- **INVESTING \$200 MILLION IN DEMENTIA RESEARCH OVER THE NEXT FIVE YEARS AND**
- **ESTABLISHING A NATIONAL ACTION FRAMEWORK ON DEMENTIA THAT WILL RESULT IN A HEALTH SYSTEM BETTER EQUIPPED TO RESPOND TO THE NEEDS OF PEOPLE WITH DEMENTIA.**

WE HAVE WELCOMED THE COMMITMENT BY THE COALITION THAT IF ELECTED THEY WILL COMMIT \$200 MILLION TO DEMENTIA RESEARCH.

WE ALSO WELCOMED THE GOVERNMENT'S ANNOUNCEMENT YESTERDAY THAT IF RE-ELECTED IT WILL HONOUR THE LEGACY OF HAZEL HAWKE BY INCREASING INVESTMENT IN DEMENTIA AND IN THE COGNITIVE AND RELATED FUNCTIONAL DECLINE IN OLDER PEOPLE WITH NEW SCHOLARSHIPS, A NEW CHAIR IN APPLIED RESEARCH AND NEW SUPPORT TO HELP TRANSLATE ACADEMIC LEARNINGS INTO BETTER PRACTICE – SO AS TO CREATE AN EXPANDED HAZEL HAWKE DEMENTIA PARTNERSHIP CENTRE.

IT HAS ALSO SAID IT WILL MATCH DOLLAR FOR DOLLAR PRIVATE AND CORPORATE DONATIONS (UP TO \$4 MILLION OVER TWO YEARS) TO HELP CREATE AND ENDOW A NEW HAZEL HAWKE CHAIR IN TRANSLATIONAL DEMENTIA RESEARCH AT A LEADING UNIVERSITY.

I WANT TO ENCOURAGE YOU ALL TO VISIT OUR WEBSITE [\(\[fightdementia.org.au\]\(http://fightdementia.org.au\)\)](http://fightdementia.org.au) AND TO SIGN UP AS A DEMENTIA CHAMPION.

I WOULD ALSO ENCOURAGE YOU TO WRITE TO YOUR LOCAL MP AFTER THE ELECTION TO HIGHLIGHT THE NEED TO ADDRESS ISSUES IMPORTANT TO BOTH DEMENTIA AND PALLIATIVE CARE SERVICES...BECAUSE IT IS ONLY BY BEING ENGAGING IN A POSITIVE WAY WITH POLITICIANS AND HARNESSING THE STORIES AND EXPERIENCES OF OUR CONSUMERS AND USING THE POWERFUL MESSAGES THEY PROVIDE, THAT WE WILL ACHIEVE THE SOCIAL CHANGE WE ARE ALL SEEKING.

THANK YOU.