

End-Of-Life Care for People with Dementia Launch

LAUNCH END-OF-LIFE CARE FOR PEOPLE WITH DEMENTIA LAUNCH

**JOINT ALZHEIMER'S AUSTRALIA AND PALLIATIVE CARE AUSTRALIA
PARLIAMENTARY FRIENDS MEETING**

**HOUSE OF REPRESENTATIVES ALCOVE
PARLIAMENT HOUSE, CANBERRA**

12 FEBRUARY 2014

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NATIONAL PRESIDENT – ALZHEIMER'S AUSTRALIA**

I AM PLEASED TO HAVE THE OPPORTUNITY TO SPEAK TO YOU TODAY ABOUT END-OF-LIFE CARE FOR PEOPLE WITH DEMENTIA.

MY THANKS TO OUR PARLIAMENTARY FRIENDS OF DEMENTIA AND THE PARLIAMENTARY FRIENDS OF END-OF-LIFE CARE, AND THANKS TO PALLIATIVE CARE AUSTRALIA FOR COSPONSORING THIS EVENT WITH ALZHEIMER'S AUSTRALIA.

DEMENTIA IS A TERMINAL ILLNESS AND RANKS AS THE THIRD LEADING CAUSE OF DEATH IN AUSTRALIA. YET FAMILIES CARING FOR A PERSON WITH DEMENTIA STRUGGLE TO GET ACCESS TO THE SAME TYPES OF SUPPORT THAT ARE AVAILABLE FOR PEOPLE WITH OTHER TERMINAL ILLNESSES SUCH AS CANCER.

CAN YOU IMAGINE YOUR PARTNER OR PARENT BEING TURNED AWAY FROM A HOSPICE BECAUSE "THEY ARE NOT DYING QUICKLY ENOUGH?" THAT'S JUST ONE OF THE MANY CONFRONTING STORIES ABOUT DIFFICULTY GETTING ACCESS TO APPROPRIATE END-OF-LIFE CARE THAT I HAVE HEARD FROM FAMILIES OF PEOPLE WITH DEMENTIA.

DEMENTIA IS DIFFERENT FROM OTHER TERMINAL CONDITIONS. IT HAS AN UNPREDICTABLE TRAJECTORY AND THERE CAN BE DIFFICULT ISSUES AROUND CAPACITY, DECISION-MAKING AND COMMUNICATION. PEOPLE WITH DEMENTIA DON'T ALWAYS FIT INTO THE TRADITIONAL MODEL OF PALLIATIVE CARE, IN SPITE OF AN EQUAL NEED FOR PALLIATIVE CARE SERVICES.

IN SEPTEMBER LAST YEAR I HAD THE PRIVILEGE OF SHARING THE STAGE WITH ONE OF AUSTRALIA'S EMINENT PALLIATIVE CARE SPECIALISTS AND ALSO SENIOR AUSTRALIAN OF THE YEAR 2013, PROFESSOR IAN MADDOCKS, AT THE PALLIATIVE CARE AUSTRALIA CONFERENCE TO LAUNCH A JOINT STATEMENT THAT CALLED FOR BETTER ACCESS TO SERVICES FOR PEOPLE WITH DEMENTIA.

IT STRESSED THE NEED FOR PALLIATIVE CARE FOR PEOPLE WITH DEMENTIA THAT IS HOLISTIC, MULTIDISCIPLINARY AND PERSON-CENTRED. IT ALSO EMPHASISED THE NEED FOR PALLIATIVE CARE TO BE AVAILABLE WHEN AND WHERE IT IS NEEDED.

THESE NEEDS ARE NOT NEW; QUALITY END-OF-LIFE CARE HAS BEEN ON ALZHEIMER'S AUSTRALIA'S AGENDA FOR MANY YEARS.

IN 2011 WE UNDERTOOK NATIONWIDE CONSULTATIONS ON AGED CARE AND END-OF-LIFE CARE.

ONE WOMAN TOLD US: *"I AM FIGHTING FOR MY MOTHER TO DIE IN A PALLIATIVE FACILITY BECAUSE I'M TOLD SHE IS NOT WORTHY, BECAUSE SHE HAS DEMENTIA."*

ANOTHER TALKED ABOUT THE ISSUE OF PLANS NOT BEING CARRIED THROUGH, *"MY MOTHER'S WISHES WERE NOT TAKEN NOTE OF. I HAD TO PLEA THAT MUM WOULD NOT BE TAKEN TO HOSPITAL IN AN AMBULANCE. THEY WERE GIVING HER ANTIBIOTICS TO KEEP HER ALIVE."*

DURING MY TIME AS NATIONAL PRESIDENT OF ALZHEIMER'S AUSTRALIA SOME OF THE MOST DIFFICULT AND MOVING STORIES I'VE HEARD HAVE BEEN ABOUT END-OF-LIFE CARE.

THE PAIN AND LINGERING GUILT THAT FAMILIES FEEL WHEN THEY ARE UNABLE TO ENSURE THAT THE WISHES OF THE PERSON WITH DEMENTIA ARE BEING RESPECTED IS IMPOSSIBLE TO IGNORE OR TO FORGET.

EQUALLY DIFFICULT ARE THE STORIES FROM FAMILIES WHO DIDN'T KNOW WHAT THE PERSON WANTED BECAUSE THE DISCUSSION WASN'T MADE EARLY ENOUGH.

HOWEVER, THE STORIES AREN'T ALL BAD. I'VE HEARD SOME WONDERFUL EXAMPLES OF HOW AGED CARE STAFF AND PALLIATIVE CARE SPECIALISTS HAVE MADE SUCH A DIFFERENCE TO PEOPLE'S LIVES AT THIS CHALLENGING TIME.

IT IS SO APPARENT HOW BADLY THINGS CAN GO IF NOT HANDLED WELL, BUT WHAT A PEACEFUL AND DIGNIFIED DEATH PEOPLE WITH DEMENTIA CAN HAVE WHEN THINGS ARE PLANNED AND APPROPRIATE SERVICES ARE AVAILABLE.

WE HAVE AN ARSENAL OF STORIES, BUT NOT ENOUGH HARD EVIDENCE ABOUT WHAT IS GOING WRONG AND WHY THE SYSTEM IS FAILING, WHICH IS WHY ALZHEIMER'S AUSTRALIA FELT IT WAS TIME TO TRY TO GET A BETTER UNDERSTANDING OF END-OF-LIFE CARE FROM THE PERSPECTIVE OF THE CONSUMER AS WELL AS THE HEALTH CARE PROFESSIONAL.

WE COMMISSIONED PIAZZA RESEARCH TO SURVEY HEALTH PROFESSIONALS AND FAMILY CARERS ON END-OF-LIFE ISSUES FOR PEOPLE WITH DEMENTIA. WE WERE OVERWHELMED WITH THE INTEREST IN THIS WORK, AND RECEIVED MORE THAN 1000 RESPONSES FROM AROUND AUSTRALIA.

THE SURVEY RESULTS CONFIRMED WHAT WE'VE HEARD ANECDOTALLY- CONSUMERS HAVE DIFFICULTY ACCESSING APPROPRIATE END-OF-LIFE CARE, BOTH WITHIN RESIDENTIAL CARE AND IN THE COMMUNITY.

IT ALSO REVEALED A STRIKING GAP BETWEEN THE PERCEPTIONS OF CARE PROFESSIONALS AND FAMILY CARERS ABOUT END-OF-LIFE CARE FOR PEOPLE WITH DEMENTIA.

FOR INSTANCE, WHILE 58 PER CENT OF FORMER CARERS SAID THAT THEY DIDN'T HAVE ACCESS TO PALLIATIVE CARE SPECIALISTS, AND 68 PER CENT DIDN'T HAVE ACCESS TO HOSPICES, THREE QUARTERS OF CARE PROFESSIONALS INDICATED THAT PEOPLE WITH DEMENTIA IN THEIR SERVICE SETTINGS DO HAVE ACCESS TO PALLIATIVE CARE.

THIS DISCREPANCY BEGS THE QUESTION OF WHETHER CONSUMERS MIGHT NOT BE AWARE OF SERVICES THAT ARE AVAILABLE, OR WHETHER IN FACT THE SERVICES ARE NOT ADEQUATELY RESOURCED TO PROVIDE SUPPORT TO ALL THE PEOPLE WHO NEED IT.

BUT EVEN WHEN PEOPLE DO HAVE ACCESS TO END-OF-LIFE CARE IT'S NOT ALWAYS CONSISTENT WITH THEIR WISHES. NEARLY A THIRD OF HEALTH PROFESSIONALS INDICATED THAT THEY HAD EXPERIENCED A SITUATION WHERE THEY WERE UNABLE TO FOLLOW THE END-OF-LIFE CARE WISHES OF A PERSON WITH DEMENTIA.

PERHAPS THE MOST SURPRISING RESULT OF THE SURVEY WAS THE LACK OF AWARENESS AROUND LEGAL RIGHTS AT THE END-OF-LIFE.

ANECDOTAL REPORTS INDICATE THAT CARE PROFESSIONALS ARE AT TIMES RELUCTANT TO USE PAIN MEDICATIONS SUCH AS MORPHINE BECAUSE OF CONCERNS ABOUT HASTENING THE DEATH OF THE PERSON THEY ARE LOOKING AFTER.

HOWEVER, ACCESS TO APPROPRIATE PAIN RELIEF IS CONSIDERED TO BE A FUNDAMENTAL HUMAN RIGHT, EVEN IF DEATH IS HASTENED AS A SECONDARY EFFECT OF MEDICATION.

OUR SURVEY FOUND THAT 27 PER CENT OF CARE PROFESSIONALS WERE UNSURE OR DID NOT BELIEVE PEOPLE ARE LEGALLY ENTITLED TO ADEQUATE PAIN CONTROL, IF THERE WERE A CHANCE IT MIGHT ALSO HASTEN DEATH.

SO PERHAPS IT ISN'T SURPRISING THEN, THAT A QUARTER OF FORMER FAMILY CARERS FELT THAT PAIN WAS NOT ADEQUATELY MANAGED AT THE END-OF-LIFE.

LACK OF AWARENESS OF LEGAL RIGHTS EXTENDS BEYOND JUST PAIN MANAGEMENT. ALMOST A THIRD OF CARE PROFESSIONALS WEREN'T AWARE THAT PEOPLE HAVE A LEGAL RIGHT TO REFUSE FOOD AND HYDRATION, AND ONE IN 10 ALSO THOUGHT REFUSAL OF ANTIBIOTICS WAS NOT A LEGAL OPTION FOR PEOPLE AT END-OF-LIFE.

I FIND THESE STATISTICS SHOCKING. HOW CAN WE EVER ACHIEVE CONSUMER EMPOWERMENT AND CONSUMER-DIRECTED CARE IF HEALTH PROFESSIONALS ARE UNAWARE OF A PERSON'S LEGAL RIGHT TO CHOOSE OR REFUSE MEDICAL TREATMENT?

THERE IS A CLEAR NEED FOR GREATER INFORMATION AND TRAINING ON LEGAL OPTIONS. OVER A THIRD OF CARE PROFESSIONALS SAID THEY HADN'T RECEIVED ANY TRAINING ON THE LEGAL RIGHTS OF A PERSON WITH DEMENTIA AT END-OF-LIFE.

THESE ARE COMPLEX ISSUES BUT WE DO NEED TO CONFRONT THEM.

RECENTLY BOTH THE AMA AND THE ROYAL AUSTRALIAN COLLEGE OF GENERAL PRACTITIONERS (RACPG) HAVE ACKNOWLEDGED THE NEED FOR GREATER TRAINING AND SUPPORT FOR DOCTORS ON ISSUES RELATING TO END-OF-LIFE CARE.

I AM PLEASED THAT AS PART OF THE 2012 AGED CARE REFORMS PACKAGE FUNDING IS GOING TOWARDS THE ESTABLISHMENT OF AN INFORMATION HOTLINE AND WEBSITE RESOURCE FOR DOCTORS AND AGED CARE PROVIDERS WHO NEED MORE INFORMATION ABOUT END-OF-LIFE CARE.

WE ALSO MUST RECOGNISE THAT IN MANY CASES DOCTORS AND CARE WORKERS ARE ALREADY PROVIDING HIGH QUALITY CARE. 64 PER CENT OF FORMER CARERS WERE SATISFIED OR VERY SATISFIED WITH THE CARE THE PERSON WITH DEMENTIA RECEIVED AT THE END-OF-LIFE.

I THINK THAT CLEARLY SHOWS MANY PEOPLE ARE RECEIVING GOOD CARE AND THAT THE MAJORITY OF CARE STAFF, BOTH IN AGED CARE AND THE COMMUNITY, ARE PROVIDING INCREDIBLE SUPPORT AT END-OF-LIFE.

WE JUST NEED TO MAKE SURE THAT EVERYONE HAS ACCESS TO THIS LEVEL OF CARE.

IT'S OBVIOUS THAT DISCUSSING, PLANNING AND DOCUMENTING OUR PREFERENCES FOR END-OF-LIFE CARE ARE THE BEST WAYS OF MINIMISING THE BURDEN OF DECISION MAKING ON OUR FAMILIES AND LOVED ONES, AND ENSURING OUR PREFERENCES ARE RESPECTED AND OUR WISHES ARE CARRIED THROUGH.

ADVANCE CARE PLANNING IS ESSENTIALLY AN INSURANCE POLICY THAT HELPS TO PROTECT US IN CASE WE LOSE DECISION- MAKING CAPACITY THROUGH ACCIDENT OR THROUGH AN ILLNESS LIKE DEMENTIA.

BECAUSE EVEN THOUGH A PERSON MIGHT TRUST A LOVED ONE – OR ONES – TO HAVE THEIR BEST INTERESTS AT HEART, THE EVIDENCE SHOWS THAT WE'RE SIMPLY NOT THAT GOOD AT GUESSING THE WISHES OF THOSE WE LOVE ON MATTERS SUCH AS RESUSCITATION, INFECTION CONTROL, ARTIFICIAL NUTRITION AND HYDRATION.

DISCUSSING AND PREFERABLY DOCUMENTING OUR PREFERENCES AND WISHES WITH FAMILY MEMBERS, FRIENDS AND CARE PROFESSIONALS IS THE BEST WAY TO ENSURE OUR WISHES WILL BE FOLLOWED AT END-OF-LIFE.

HOWEVER OUR SURVEY FOUND ALMOST TWO THIRDS OF PEOPLE WITH DEMENTIA DID NOT HAVE AN ADVANCE CARE PLAN, AS REPORTED BY THEIR CARERS, AND MOST OF THOSE WHO DID LEFT THIS UNTIL VERY LATE STAGES OF THEIR DISEASE.

AT THE SAME TIME, THE LACK OF ADVANCE PLANNING WAS IDENTIFIED BY BOTH CONSUMERS AND HEALTH PROFESSIONALS AS ONE OF THE BARRIERS TO GOOD END-OF-LIFE CARE.

I'VE HEARD TOO MANY STORIES OF CARERS BEING WRACKED WITH GUILT BECAUSE AN ADVANCE CARE PLAN WAS NOT PUT IN PLACE WHEN THE OPPORTUNITY WAS THERE.

AND TODAY I'M PROUD TO BE LAUNCHING ALZHEIMER'S AUSTRALIA'S NEW START 2 TALK PROGRAM – A NATIONAL, EVIDENCE-BASED PROGRAM THAT HELPS PEOPLE TO BEGIN THE CONVERSATIONS WE ALL NEED TO HAVE ABOUT OUR FUTURE HEALTHCARE, LIFESTYLE , FINANCIAL PREFERENCES AND DECISIONS.

IT WAS DEVELOPED BY DR CHRIS SHANLEY FROM SYDNEY'S LIVERPOOL HOSPITAL AFTER ADVANCE CARE PLANNING WAS IDENTIFIED AS A KEY PRIORITY AREA FOR DEMENTIA CARE BY MEMBERS OF OUR CONSUMER DEMENTIA RESEARCH NETWORK.

DR SHANLEY CONSULTED WITH CONSUMERS, AGED CARE PROVIDERS, CLINICIANS AND POLICY MAKERS AUSTRALIA-WIDE, TO FIRST IDENTIFY THE ISSUES, THEN TO ESTABLISH A FRAMEWORK OF ADVANCE PLANNING, AND FINALLY TO DEVELOP THE WEBSITE AND CAMPAIGN THAT I AM LAUNCHING TODAY.

I'D LIKE TO SHARE WITH YOU A PROMOTIONAL VIDEO THAT EXPLAINS THE PROGRAM. YOU WILL ALSO FIND THIS ON THE START 2 TALK WEBSITE.

SHOW VIDEO – 59 SECONDS

AS YOU'VE JUST SEEN START 2 TALK PROMOTES A BROAD PERSPECTIVE ON ADVANCE PLANNING, BUT PARTICULARLY PLANNING FOR FUTURE HEALTH AND END-OF-LIFE DECISIONS.

A SERIES OF WORKSHEETS THAT GUIDE PEOPLE THROUGH THE PROCESS OF PLANNING AHEAD FOR THEMSELVES OR FOR A LOVED ONE IS INCLUDED ON THE WEBSITE. THERE IS ALSO DETAILED INFORMATION ABOUT REQUIREMENTS AND DOCUMENTATION FOR EACH STATE AND TERRITORY, AND A COMPREHENSIVE SECTION AIMED AT HEALTHCARE PROFESSIONALS.

THIS IS AN EXCITING, NATIONAL DEVELOPMENT ADDRESSING A KEY ISSUE FOR CONSUMERS, AND ALZHEIMER'S AUSTRALIA HOPES TO BE ABLE TO CONTINUE PROMOTING AND DEVELOPING START 2 TALK FOR YEARS TO COME.

MY THANKS TO DR CHRIS SHANLEY FOR HIS WORK ON THE PROJECT, TO THE JO & JR WICKING TRUST AND BUPA CARE SERVICES FOR THEIR SUPPORT OF THE NATIONAL QUALITY DEMENTIA CARE INITIATIVE THROUGH WHICH THE PROJECT WAS FUNDED, AND TO THE NUMEROUS ORGANISATIONS WHO HAVE JOINED US AS SUPPORTERS OF THE PROGRAM; MANY REPRESENTED HERE TODAY.

**GOOD PALLIATIVE CARE IS NOT JUST ABOUT ENSURING A GOOD DEATH,
BUT ABOUT PROMOTING QUALITY OF LIFE UNTIL THE VERY END.**

**THE RESULTS OF OUR SURVEY ILLUSTRATE THAT FOR MANY PEOPLE
WITH DEMENTIA WE'RE FAILING TO ACHIEVE THIS GOAL.**

**BUT I WELCOME THE NEW INSIGHTS IT HAS PROVIDED SHOWING US
WHERE WE NEED TO GO NEXT IN OUR ADVOCACY.**

**WE NEED TO SUPPORT CONSUMERS TO DOCUMENT THEIR WISHES FOR
END-OF-LIFE CARE EARLY IN THE DISEASE... AND I HOPE THAT START 2
TALK WILL HELP THEM DO THAT.**

**BUT WE ALSO NEED TO SUPPORT HEALTH PROVIDERS AND ENSURE
ADEQUATE RESOURCING AND TRAINING SO THAT ALL PEOPLE WITH
DEMENTIA HAVE ACCESS TO THE SPECIALISTS AND HOSPICE SERVICES
THAT THEY REQUIRE.**

**HEALTH PROFESSIONALS NEED TO BE SUPPORTED TO NAVIGATE THE
COMPLEX LEGAL ISSUES THAT END-OF-LIFE CARE FOR DEMENTIA CAN
RAISE.**

I'M SURE WE'D ALL AGREE THAT PEOPLE WITH DEMENTIA DESERVE THE SAME ACCESS TO APPROPRIATE END-OF-LIFE CARE AS ANYONE ELSE;

THAT THEY DESERVE TO HAVE THEIR WISHES RESPECTED

AND MOST OF ALL THEY DESERVE THE PRESERVATION OF DIGNITY THAT ALL OF US WOULD EXPECT, REGARDLESS OF A DISEASE.

THE EMPHASIS ON PALLIATIVE CARE IN THE 2012 AGED CARE REFORMS PACKAGE GIVES ME SOME HOPE... I FEAR THOUGH WE HAVE A LONG ROAD AHEAD OF US BEFORE ACHIEVING THIS GOAL...BUT WE WILL BE WORKING HARD TO GET TO IT.

THANK YOU.