

HOW AUSTRALIA CAN BEAT DEMENTIA

**ALP FRINGE EVENT –
DEMENTIA: THE CHRONIC DISEASE OF THE 21ST CENTURY**

**SYDNEY CONVENTION AND EXHIBITION CENTRE
PARKSIDE, DARLING HARBOUR
ROOM 110B**

DECEMBER 2, 2011

**ITA BUTTROSE
PRESIDENT – ALZHEIMER'S AUSTRALIA**

GOOD AFTERNOON EVERYONE. THANK YOU FOR COMING TO HEAR WHAT WE HAVE TO SAY ABOUT DEMENTIA.

IN NATIONAL POLITICS IT SEEMS TO ME THAT LEADERSHIP AND VISION ARE THROWN AROUND LIKE CONFETTI. IF THIS GOVERNMENT IS SEEKING AN AREA IN WHICH TO BE A CHAMPION AND TO BUILD ON THEIR EXISTING COMMITMENT TO HEALTH CARE REFORMS THEN THERE IS NO GREATER CHALLENGE THAN DEMENTIA.

IT WAS TO DRAW ATTENTION TO THE NEED TO FIGHT DEMENTIA THAT ALZHEIMER'S AUSTRALIA ORGANISED ITS HISTORIC MARCH ON PARLIAMENT HOUSE IN CANBERRA A FEW WEEKS AGO.

ON A PERSONAL LEVEL IT WAS THE FIRST TIME MY PASSION FOR A CAUSE INSPIRED ME TO MARCH AND IT WAS ENCOURAGING TO HAVE SUPPORT FOR OUR CAUSE FROM BOTH SIDES OF PARLIAMENT.

500 HUNDRED AUSTRALIANS FROM ALL OVER AUSTRALIA STEPPED OUT TO DEMAND CHANGE.

IN CANBERRA, I ASSURED THE MARCHERS THAT THERE WILL BE NO GOING BACKWARDS BECAUSE THERE IS SO MUCH WE CAN DO AS A COUNTRY TO BEAT DEMENTIA. TODAY, AS PRESIDENT OF ALZHEIMER'S AUSTRALIA, I WOULD LIKE TO SHARE WITH YOU MY VISION OF HOW WE CAN WORK TOGETHER TO DO THIS.

DEMENTIA IS THE MAJOR CHRONIC DISEASE OF THIS CENTURY. THERE ARE MORE THAN A QUARTER OF A MILLION PEOPLE LIVING WITH DEMENTIA TODAY AND BY 2050 THERE WILL BE NEARLY A MILLION.

DEMENTIA IS A PROBLEM HERE AND NOW. IN EIGHT YEARS' TIME THERE WILL BE 75,000 BABY BOOMERS WITH DEMENTIA; WITHIN 10 YEARS THE NUMBER OF PEOPLE WITH DEMENTIA WILL INCREASE BY 50 PER CENT TO NEARLY 400,000.

DEMENTIA IS A TERMINAL DISEASE. IT IS ALREADY THE THIRD LEADING CAUSE OF DEATH IN AUSTRALIA.

YET FOR SOME REASON MANY CHOOSE TO TURN AWAY FROM THIS ILLNESS OR SIMPLY SAY... WELL IT IS AN UNAVOIDABLE CONSEQUENCE OF AGEING. THIS IS INCORRECT. DEMENTIA IS NOT A NORMAL PART OF AGEING.

I AM NOT SURE IF DEMENTIA IS IGNORED BECAUSE OF AGEISM, IGNORANCE OR JUST AN UNWILLINGNESS TO FACE SUCH A DIFFICULT ISSUE. BUT THE FACT REMAINS THAT DEMENTIA HAS – AND WILL CONTINUE TO HAVE – A SIGNIFICANT HEALTH AND SOCIAL IMPACT ON OUR COUNTRY.

BY 2030, IT WILL BE THE THIRD HIGHEST COST TO OUR HEALTH CARE SYSTEM.

I WARMLY WELCOME THE FACT THAT THE ALP HAS INCLUDED DEMENTIA AS PART OF THE DRAFT LABOR PARTY PLATFORM WHICH IS UNDER CONSIDERATION AT THIS CONFERENCE. I BELIEVE THIS IS A FIRST FOR THE ALP.

NOW WE NEED YOUR PARTY TO ADOPT THIS PART OF THE PLATFORM AND TO ACT ON IT.

OUR “FIGHT DEMENTIA CAMPAIGN” ADDRESSES FIVE PRIORITY AREAS WHICH I BELIEVE ARE CONSISTENT WITH YOUR DRAFT PLATFORM:

- 1) AWARENESS**
- 2) DIAGNOSIS**
- 3) CARE**
- 4) RESEARCH**
- 5) RISK REDUCTION**

FIRSTLY, ALZHEIMER’S AUSTRALIA NEEDS TO BE SUPPORTED IN ITS EFFORTS TO TACKLE COMMUNITY IGNORANCE ABOUT DEMENTIA. DEMENTIA NEEDS TO BE TALKED ABOUT.

CHILDREN NEED TO BE EDUCATED ABOUT DEMENTIA AT SCHOOL, SO THEY UNDERSTAND THAT WHAT’S HAPPENING TO THEIR GRANDPARENTS IS NOT SOMETHING TO BE ASHAMED ABOUT.

THE REALTY IS HOWEVER, MANY PEOPLE FEEL TOO EMBARRASSED AND AFRAID TO SAY ANYTHING WHEN SOMEONE THEY LOVE IS DIAGNOSED WITH DEMENTIA.

WE HAVE TO CHANGE THIS. WE CHANGED PUBLIC ATTITUDES IN AUSTRALIA TO CANCER BY RAISING AWARENESS AND TALKING ABOUT IT. WE NEED TO DO EXACTLY THE SAME THING FOR DEMENTIA. IT IS THE BEST WAY TO CHANGE ATTITUDES TO THE DISEASE.

THE FIRST EXPERIENCE OF A DIAGNOSIS OF DEMENTIA IS TO BECOME SOCIALLY ISOLATED.

SADLY, IT IS NOT JUST LAY PEOPLE THAT ARE IGNORANT. OUR MEDICAL STAFF NEED TO BETTER UNDERSTAND DEMENTIA AND HOW TO COMMUNICATE WITH PEOPLE WHO HAVE DEMENTIA.

DOCTORS OFTEN HAVE DIFFICULTY DIAGNOSING DEMENTIA; SOME ARE NOT AWARE OF THE BENEFITS OF A DIAGNOSIS OF A CONDITION THAT DOES NOT HAVE A CURE.

ALZHEIMER'S AUSTRALIA RELEASED A REPORT THIS YEAR THAT SHOWED IT CAN TAKE UP TO THREE YEARS FROM A PERSON FIRST NOTICING SYMPTOMS UNTIL GETTING A DIAGNOSIS. WE HAVE HEARD STORIES CORROBORATING THIS OVER AND OVER AGAIN AT OUR RECENT CONSULTATIONS ACROSS AUSTRALIA ON AGED CARE REFORM.

ONE MAN TOLD US THAT WHEN HE TOOK HIS WIFE TO THEIR GP IT WAS 18 MONTHS BEFORE HE COULD SEE A SPECIALIST. WHEN THEY FINALLY GOT TO THE SPECIALIST, HIS WIFE WAS GIVEN A NUMBER OF TESTS, AND STILL THEY WERE TOLD THERE WAS NOTHING WRONG.

TO ADDRESS THE BARRIERS TO TIMELY DIAGNOSIS WE NEED TO EMPLOY SPECIALIST DEMENTIA NURSES AND PROVIDE TRAINING AND EDUCATION FOR ALL HEALTH PROFESSIONALS.

WE NEED ACCESS TO QUALITY DEMENTIA CARE SERVICES. THIS INCLUDES GREATLY EXPANDED COMMUNITY CARE SERVICES AND IN PARTICULAR RESPITE CARE.

THESE SERVICES IN OUR COMMUNITY MUST BE FLEXIBLE, APPROPRIATE AND MEET THE DEMANDS OF PEOPLE LIVING WITH DEMENTIA AND THEIR CARERS.

ALL TOO OFTEN WE ARE TOLD RESPITE CARE SERVICES WILL NOT PROVIDE ACCESS FOR PEOPLE WITH DEMENTIA. AND THE SERVICES ARE NOT AVAILABLE WHEN AND WHERE THEY ARE NEEDED.

WE HAVE BEEN TOLD ABOUT HOSPITALS WHERE CARERS HAVE TO COME IN TO SHOWER AND FEED THE PERSON WITH DEMENTIA.

IF WE CANNOT PROVIDE GOOD CARE NOW WHAT WILL HAPPEN IN THE NEXT 20 OR 30 YEARS WHEN THE NUMBERS OF PEOPLE WITH DEMENTIA DOUBLE?

WITHOUT ACCESS TO QUALITY DEMENTIA CARE THE RESPONSIBILITY FALLS BACK ONTO THE SHOULDERS OF THE CARER. WE HEARD SO MANY DISTRESSING STORIES FROM CARERS AT OUR AGED CARE REFORM CONSULTATIONS.

THERE WERE:

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- **FAMILY CARERS IN TEARS BECAUSE THEY FELT THEY'D FAILED THE PERSON THEY LOVED AT THE END OF THEIR LIFE BECAUSE STAFF WOULD NOT OBSERVE THE WISHES OF THE PERSON CONCERNED.**
- **FAMILY CARERS WHO WATCHED IN HORROR AS THE IMMEDIATE CONSEQUENCE OF ACCESS TO RESIDENTIAL CARE WAS DETERIORATION IN THE FUNCTIONAL CAPACITY OF THEIR FAMILY MEMBER, WAS NO LONGER PERMITTED TO EXERCISE OR WHO WAS CHEMICALLY OR PHYSICALLY RESTRAINED.**
- **FAMILY CARERS WHO REPORTED THAT FAMILY MEMBERS ADMITTED AS PATIENTS TO HOSPITALS WERE LEFT UNFED OR EXPERIENCED FALLS BECAUSE STAFF WERE UNAWARE THEY HAD DEMENTIA.**

OF COURSE THERE ARE POSITIVE STORIES TOO BUT THE OVERWHELMING MESSAGE IS THAT THE HEALTH AND CARE SYSTEM IS FAILING PEOPLE WITH DEMENTIA AND THEIR FAMILY CARERS.

WE NEED TO BETTER SUPPORT OUR FAMILY CARERS, MAKING SURE THEY ARE AWARE OF WHERE THEY CAN TURN FOR HELP. LIKE HUNDREDS OF THOUSANDS CARERS, I KNOW THE STRESS AND EMOTIONAL STRAIN OF BEING A CARER AS I WAS THE PRINCIPAL CARER FOR MY FATHER WHO HAD VASCULAR DEMENTIA.

AN INVESTMENT IN RESEARCH IS CRUCIAL. AUSTRALIAN RESEARCHERS WORKING TO UNDERSTAND AND BEAT THIS TERRIBLE DISEASE NEED TO BE BETTER SUPPORTED.

COMPARED WITH OTHER CHRONIC CONDITIONS, THE LEVEL OF FUNDING FOR DEMENTIA RESEARCH IN AUSTRALIA IS UNACCEPTABLY LOW.

HOW CAN WE SERIOUSLY EXPECT TO TACKLE DEMENTIA WHEN WE SPEND ONLY \$20 MILLION A YEAR ON DEMENTIA RESEARCH THROUGH THE NATIONAL HEALTH AND MEDICAL RESEARCH COUNCIL – THIS AMOUNT IS ABOUT SEVEN TIMES LESS THAN THE AMOUNT INVESTED IN CANCER RESEARCH.

FINALLY, THE MAJORITY OF AUSTRALIANS IS NOT AWARE OF HOW THEY MAY REDUCE THEIR RISK OF DEMENTIA. WE HAVE AN OBLIGATION TO INFORM ALL AUSTRALIANS THAT DEMENTIA STARTS TO DEVELOP DECADES BEFORE SYMPTOMS BEGIN TO SHOW.

VASCULAR HEALTH, KEEPING PHYSICALLY, MENTALLY AND SOCIALLY ACTIVE, MINDING YOUR DIET, NOT SMOKING AND AVOIDING EXCESSIVE DRINKING HABITS ARE IMPORTANT WAYS TO KEEP DEMENTIA AT BAY. YET MOST AUSTRALIANS DO NOT KNOW THIS!

AT LONG LAST WE HOPE THE SCENE IS SET FOR CHANGE. THE PRIME MINISTER IS COMMITTED TO ACTION ON AGED CARE REFORM IN THIS TERM OF GOVERNMENT. WE LOOK FOR ACTION IN THE 2012 BUDGET.

WE ALSO GREATLY VALUE THE UNDERSTANDING THAT THE MINISTER FOR MENTAL HEALTH AND AGEING, MARK BUTLER, HAS FOR THE CONCERNS OF PEOPLE LIVING WITH DEMENTIA. HE HAS STATED PUBLICALLY THAT AGED CARE REFORM WITHOUT DEMENTIA AT ITS HEART WILL NOT BE SUCCESSFUL. HE IS ABSOLUTELY RIGHT.

I APPLAUD THE ALP FOR TAKING THE STEP IN ACKNOWLEDGING THE ISSUE OF DEMENTIA IN THE DRAFT PARTY PLATFORM.

BUT AUSTRALIA NEEDS TO SEE THE GOVERNMENT TURN WORDS INTO ACTION, AND WHAT BETTER TIME THAN NOW, WHEN THE GOVERNMENT HAS COMMITTED TO AGED CARE REFORM?

GOVERNMENT FUNDING FOR A NATIONAL STRATEGY THAT TARGETS DEMENTIA AWARENESS, DIAGNOSIS, CARE, DEMENTIA RISK REDUCTION AND RESEARCH WILL GIVE AUSTRALIA A CHANCE OF BEATING DEMENTIA BEFORE IT BEATS US.

WE NEED A GOVERNMENT THAT RECOGNISES THE ISSUE OF DEMENTIA AS A HEALTH AND AN AGED CARE CHALLENGE.

A GOVERNMENT THAT FIGHTS DEMENTIA BY PROVIDING BETTER CARE TODAY IN ORDER TO REDUCE THE SCALE OF THE PROBLEM TOMORROW.

NOW THERE IS A VISION... AND A CHALLENGE.

THANK YOU.