

World Alzheimer's Day National Press Club 2016

**DEMENTIA UPDATE: THE CHALLENGES FACING AUSTRALIA**

**WORLD ALZHEIMER'S DAY  
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**I AM PLEASED TO HAVE THE OPPORTUNITY TODAY TO DELIVER THIS UPDATE ON DEMENTIA, ONE OF THE BIGGEST PUBLIC HEALTH CHALLENGES FACING AUSTRALIA.**

**IT IS A TERMINAL, PROGRESSIVE CONDITION THAT CAUSES COGNITIVE DECLINE.**

**DEMENTIA AFFECTS SEVEN IN 10 PEOPLE IN AUSTRALIA IN SOME WAY. 1800 NEW CASES ARE DIAGNOSED EVERY WEEK; ONE IN THREE PEOPLE OVER 85 HAS DEMENTIA; ALMOST ONE IN 10 PEOPLE OVER 65 HAS DEMENTIA.**

**CURRENTLY 353,800 AUSTRALIANS ARE LIVING WITH DEMENTIA. IT'S ESTIMATED THAT MORE THAN 1.2 MILLION PEOPLE ARE INVOLVED IN THEIR CARE. IN THE NEXT 30 YEARS THE NUMBER OF PEOPLE LIVING WITH DEMENTIA WILL TRIPLE.**

**THE MOST COMMON FORM OF DEMENTIA IS ALZHEIMER'S DISEASE, REPRESENTING 70 PER CENT OF AUSTRALIA'S PRESENT CASE LOAD.**

**THE ESTIMATED COST OF DEMENTIA TO OUR HEALTH AND AGED CARE SYSTEM IS AROUND FIVE BILLION DOLLARS ANNUALLY. IN THE NEXT 20 YEARS IT WILL BECOME THE THIRD GREATEST SOURCE OF HEALTH AND RESIDENTIAL AGED CARE SPENDING, WITH THE COSTS TO THESE SECTORS ALONE REACHING ONE PER CENT OF GDP.**

**THE NUMBERS ARE GRIM AND SPELL OUT THE MAGNITUDE OF THE CONDITION. HOWEVER THE SOCIAL COST OF DEMENTIA IS EVEN HIGHER.**

**IT IS DIFFICULT TO IMAGINE ANOTHER CHRONIC CONDITION CLOUDED BY AS MUCH STIGMA AND MISUNDERSTANDING AS DEMENTIA.**

**A RECENT ROY MORGAN POLL FOUND THAT 25 PER CENT OF AUSTRALIANS THOUGHT PEOPLE WITH DEMENTIA ARE FRIGHTENING. THINK ABOUT THAT: A QUARTER OF AUSTRALIA'S POPULATION FIND YOU FRIGHTENING BECAUSE YOU HAVE BEEN DIAGNOSED WITH A MEDICAL CONDITION.**

**PEOPLE WITH DEMENTIA REPORT ON BEING EXCLUDED FROM THEIR COMMUNITIES; HOW FRIENDS OFTEN DISAPPEAR AFTER A DIAGNOSIS. THEIR CARERS EXPERIENCE A SIMILAR ISOLATION.**

**ONE PERSON PUT IT THIS WAY: "A DIAGNOSIS OF CANCER AND EVERYONE RUSHES IN TO HELP; DEMENTIA AND EVERYONE DISAPPEARS."**

**THAT'S WHY WE CHOSE THE MESSAGE "YOU ARE NOT ALONE" FOR DEMENTIA AWARENESS MONTH (WHICH IS THIS MONTH) TO REMIND PEOPLE WITH DEMENTIA AND THEIR CARERS, THEY AREN'T ALONE. ALZHEIMER'S AUSTRALIA OFFERS MANY SUPPORT AND EDUCATION OPTIONS TO HELP THEM MAINTAIN CONNECTIONS WITH LOVED ONES AND THE COMMUNITY.**

**AND WE URGE AUSTRALIANS WHEREVER THEY LIVE TO EMBRACE THE CONCEPT OF DEMENTIA-FRIENDLY COMMUNITIES, ONE OF OUR CURRENT PRIORITIES, SO THAT A PERSON WITH DEMENTIA FEELS VALUED AND RESPECTED IN THE COMMUNITY IN WHICH HE OR SHE LIVES.**

**WE ARE GREATLY ENCOURAGED IN THIS ENDEAVOUR BY THE GOVERNMENT'S ANNOUNCEMENT EARLIER THIS MONTH THAT IT WILL PROVIDE \$3.9 MILLION TO ALZHEIMER'S AUSTRALIA OVER THREE YEARS TO ESTABLISH A NATIONAL DEMENTIA-FRIENDLY COMMUNITIES PROGRAM.**

**THIS WILL HELP US GIVE AUSTRALIANS A GREATER UNDERSTANDING OF DEMENTIA AND THE SMALL THINGS THAT CAN BE DONE TO MAKE A REAL DIFFERENCE TO PEOPLE LIVING WITH THE CONDITION.**

**IT CERTAINLY WILL BE WELCOMED BY PEOPLE LIVING WITH DEMENTIA WHO I THINK MIGHT BE SOME OF THE LONELIEST MEN AND WOMEN IN OUR COUNTRY.**

**A ROY MORGAN POLL THAT WE COMMISSIONED THIS YEAR FOUND THAT COMPARED TO THE REST OF THE COMMUNITY, PEOPLE WITH DEMENTIA ARE:**

- **MORE THAN TWICE AS LIKELY NOT SEE ANY FRIENDS**
- **MORE THAN THREE TIMES MORE LIKELY TO NOT HAVE A CONFIDANT**
- **ALMOST THREE TIMES AS LIKELY TO NOT HAVE A FRIEND TO CALL ON FOR HELP**

**WE HAVE MADE HUGE PROGRESS IN AUSTRALIA SUPPORTING PEOPLE WITH PHYSICAL DISABILITIES.**

**WE NOW ACCEPT THAT THERE IS A NEED TO CREATE ACCESSIBLE SPACES WITH RAMPS AND OTHER SUPPORTS TO ENSURE PEOPLE WITH DISABILITIES ARE INCLUDED IN EVERY DAY LIVING.**

**EVEN THE FIVE DOLLAR NOTE HAS BEEN CHANGED TO BE MORE ACCESSIBLE TO PEOPLE WITH A VISUAL IMPAIRMENT.**

**THE NATIONAL DISABILITY INSURANCE SCHEME HAS BEEN ANOTHER SIGNIFICANT STEP FORWARD IN PROVIDING SUPPORT FOR PEOPLE WITH DISABILITIES.**

**BUT SOMEHOW, OUR UNDERSTANDING AND SUPPORT FOR PEOPLE WITH INTELLECTUAL DISABILITIES, INCLUDING THOSE WITH DEMENTIA, REMAINS LIMITED.**

**EVEN THOUGH DEMENTIA IS THE SINGLE GREATEST CAUSE OF DISABILITY IN OLDER AUSTRALIANS MOST PEOPLE DON'T THINK OF DEMENTIA AS A DISABILITY BUT RATHER AS A TERMINAL MEDICAL CONDITION OF OLD AGE WHERE NOTHING CAN BE DONE.**

**THIS SIMPLY ISN'T SO. PEOPLE CAN LIVE WELL WITH DEMENTIA. WHEN THEY'RE GIVEN APPROPRIATE SUPPORT THEY CAN – LIKE THE REST OF US – LIVE MEANINGFUL LIVES. A DIAGNOSIS OF DEMENTIA DOES NOT PRECLUDE POSITIVE LIVING, JOYFUL EXPERIENCES AND LOVING RELATIONSHIPS.**

**PEOPLE WITH DEMENTIA NEED SUPPORT THAT TAKES INTO ACCOUNT THEIR PREFERENCES, THEIR GOALS, AND WHAT THEIR LIFE WAS LIKE BEFORE THEY GOT A DIAGNOSIS. AND THEY HAVE THE SAME HUMAN RIGHTS AS EVERYONE ELSE IN THE COMMUNITY.**

**HOWEVER, PEOPLE WITH DEMENTIA STRUGGLE TO GET ACCESS TO THE SERVICES AND SUPPORT THEY NEED TO ACHIEVE A HIGH QUALITY OF LIFE; SOME AGED CARE FACILITIES CONTINUE TO USE ANTIPSYCHOTIC MEDICATIONS AS A FORM OF RESTRAINT; WITHIN PRIMARY CARE PEOPLE FACE DIFFICULT DELAYS IN GETTING ACCESS TO A DIAGNOSIS, ON AVERAGE IT CAN TAKE UP TO THREE YEARS – WORRYING YEARS SPENT WAITING AND WONDERING WHAT IS WRONG.**

**ALZHEIMER'S AUSTRALIA WELCOMED THE 2012 AGED CARE REFORMS AS DID PEOPLE LIVING WITH DEMENTIA. WE HOPED THEY WOULD LEAD TO SIGNIFICANT CHANGES AND IMPROVEMENTS IN THE HEALTH AND AGED CARE SYSTEMS FOR PEOPLE WITH DEMENTIA.**

**FOUR YEARS LATER THE PROMISE OF THOSE REFORMS HAS NOT BEEN REALISED; MANY PEOPLE FEEL LET DOWN.**

**THERE ARE SOME SUCCESS STORIES. THE NATIONAL COMMISSION ON QUALITY AND SAFETY IN HEALTH CARE HAS SHOWN LEADERSHIP IN IMPROVING THE CARE OF PEOPLE WITH DEMENTIA IN HOSPITALS. THERE HAVE BEEN IMPROVEMENTS IN ACCESS TO COMMUNITY CARE, AND CONSUMER-DIRECTED CARE HAS BEEN FINALLY, FULLY ROLLED OUT IN COMMUNITY CARE.**

**BUT THE FUNDAMENTAL ISSUES AROUND THE QUALITY OF CARE REMAIN. WE CONTINUE TO HAVE AN AGED CARE SYSTEM WHERE A MEDICAL MODEL OF CARE IS PROMOTED THROUGH BOTH THE FUNDING INSTRUMENT AND THE AGED CARE STANDARD.**

**CURRENTLY THERE IS NOT A SINGLE, MANDATED PUBLICLY-REPORTED MEASURE OF QUALITY IN PLACE FOR AGED CARE IN AUSTRALIA. THE GOVERNMENT HAS BEEN WORKING TO DEVELOP QUALITY INDICATORS BUT THE FOCUS ON CLINICAL OUTCOMES HAS BEEN DISAPPOINTING, TO SAY THE LEAST.**

**WE NEED A COMMON DEFINITION OF QUALITY THAT FOCUSES ON THE SOCIAL NEEDS OF PEOPLE LIVING WITHIN AGED CARE WHILE ALSO ENSURING THEY RECEIVE APPROPRIATE MEDICAL CARE.**

**PRIOR TO THE RECENT FEDERAL ELECTION, THE GOVERNMENT ANNOUNCED IT WOULD BE CUTTING FUNDING TO PEOPLE LIVING IN RESIDENTIAL AGED CARE, IN SPITE OF THE INCREASING COMPLEXITY OF CARE NEEDED DUE TO LATER ENTRY, ENTRY STRAIGHT FROM HOSPITAL, CO-MORBIDITIES AND POLYPHARMACY THAT NOW CHARACTERISE RESIDENTIAL AGED CARE.**

**THIS CONCERNS ME BECAUSE IT SEEMS TO INDICATE THAT THE GOVERNMENT ISN'T ENGAGING WITH HOW BEST TO SUPPORT PEOPLE WITH DEMENTIA AND DOESN'T UNDERSTAND THE REALITIES OF DAY-TO-DAY LIFE IN AN AGED CARE FACILITY.**

**THE GOVERNMENT HAS REVIEWED AND UPDATED THE DEMENTIA FRAMEWORK. IT SETS OUT THE KEY PRIORITIES. IT'S MEANT TO BE A 'GUIDE' FOR THE DEVELOPMENT OF ACTIONS, PLANS AND POLICES FOR IMPROVED SUPPORT FOR PEOPLE WITH DEMENTIA.**

**IT IDENTIFIES AREAS FOR ACTION INCLUDING TIMELY DIAGNOSIS, INCREASING AWARENESS, APPROPRIATE AGED CARE SERVICES, ACCESS TO END OF LIFE CARE... BUT THERE IS NO FUNDING TO PUSH THESE RECOMMENDATIONS FORWARD.**

**AND SO PEOPLE WITH DEMENTIA ARE STUCK WITH A FRAMEWORK TRAPPED IN A NO-FUNDING LIMBO. IT'S HARDLY DEMENTIA-FRIENDLY IS IT?**

**NEITHER DOES AUSTRALIA HAVE A NATIONAL FULLY-FUNDED DEMENTIA STRATEGY, AGAIN SOMETHING THAT WE HAVE BEEN ADVOCATING, THAT WOULD TACKLE THE ISSUES IDENTIFIED IN THE DEMENTIA FRAMEWORK AND PROVIDE LEADERSHIP AND FUNDING IN SUCH AREAS AS RISK REDUCTION AND PREVENTION PLUS BETTER APPROACHES TO TREATMENT IN PRIMARY CARE. ...A STRATEGY THAT HAS KEY PERFORMANCE INDICATORS, ALLOCATES RESPONSIBILITIES AND IS DEVELOPED WITH PEOPLE WITH DEMENTIA, BASED ON EVIDENCE OF WHAT WORKS.**



**A DIAGNOSIS OF DEMENTIA IS DEVASTATING. I KNOW FROM PERSONAL EXPERIENCE HOW IT IMPACTS ON THE PERSON WITH THE DIAGNOSIS, THE FAMILY, THE CARERS.**

**DEMENTIA IS NOW THE SECOND LEADING CAUSE OF DEATH IN AUSTRALIA.**

**IF PEOPLE WITH DEMENTIA ARE TO HAVE THE SAME RIGHTS AS THE REST OF US THEY SHOULD HAVE A RIGHT...**

- **TO A TIMELY DIAGNOSIS**
- **TO POST DIAGNOSTIC SUPPORT**
- **TO SOCIAL ENGAGEMENT**

**NOW THAT WOULD BE A DEMENTIA FRIENDLY COUNTRY.**

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**LET ME ASK YOU WHAT KIND OF AUSTRALIA WOULD YOU WISH TO LIVE IN, IF YOU RECEIVED A DIAGNOSIS OF DEMENTIA TOMORROW OR IF A MEMBER OF YOUR FAMILY DID.**

**YOU WOULD HOPE IT WOULD BE A TRULY DEMENTIA-FRIENDLY AUSTRALIA WITH A FULLY FUNDED NATIONAL DEMENTIA STRATEGY AND DEMENTIA FRAMEWORK. WE CAN'T FIGHT DEMENTIA EFFECTIVELY WITHOUT THEM.**

**ACHIEVING THIS STATUS MUST BE A PRIORITY. THERE IS NO TIME TO WASTE. WE NEED ACTION.**

**THANK YOU.**