

AGED CARE REFORM – PUBLIC FORUM

**NATIONAL PRESS CLUB,
CANBERRA**

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CEO ALZHEIMER'S AUSTRALIA**

I WOULD LIKE TO ACKNOWLEDGE THE TRADITIONAL OWNERS OF THE COUNTRY ON WHICH WE ARE MEETING AND PAY MY RESPECT TO ELDERS PAST AND PRESENT.

I AM GRATEFUL TO THE PRESS CLUB FOR THE OPPORTUNITY TO SPEAK HERE TODAY WITH MY COLLEAGUES.

THE IMPLEMENTATION OF THE AGED CARE REFORM AGENDA, TOGETHER WITH DISABILITYCARE, WILL PRESENT EXCITING YET DAUNTING CHALLENGES FOR THE NEW GOVERNMENT.

EXCITING BECAUSE FOR THE FIRST TIME IN AUSTRALIAN SOCIAL POLICY WE HAVE AN OPPORTUNITY TO REFOCUS AGED CARE AND DISABILITY CARE FROM ONE SIZE FITS ALL CARE TO ONE WHICH SUPPORTS PEOPLE TO ACHIEVE THEIR INDIVIDUAL GOALS AND TO HAVE AS MUCH INDEPENDENCE AND QUALITY OF LIFE AS THEY CAN GIVEN THEIR INDIVIDUAL CIRCUMSTANCES.

FOR PEOPLE WITH DEMENTIA OF ALL AGES AND THEIR FAMILY CARERS THERE IS THE PROSPECT OF BEING ABLE TO ACCESS THE CARE AND SUPPORT THEY NEED AND TO BE AN EQUAL PARTNER IN CARE WITH THE SERVICE PROVIDER.

THE TASK IS DAUNTING FOR A NUMBER OF REASONS.

OUR CONSULTATIONS ON THE AGED CARE REFORMS HAS HIGHLIGHTED JUST HOW BADLY THE CURRENT SYSTEM IS PERFORMING FOR OLDER PEOPLE AND THE MORE THAN 320,000 AUSTRALIANS WITH DEMENTIA.

IT IS DAUNTING TOO BECAUSE THE AUSTRALIAN POPULATION IS RAPIDLY AGEING. FOR EXAMPLE, THE NUMBERS OF THOSE AGED 85 AND OLDER WILL DOUBLE OVER THE NEXT TWENTY YEARS, GROWING FROM APPROXIMATELY 455,000 IN 2013 TO OVER 930,000 IN 2033.

ALTHOUGH DEMENTIA IS NOT A NATURAL PART OF AGEING AND AFFECTS 24,000 PEOPLE UNDER 65 YEARS, AGE IS THE BIGGEST RISK FACTOR FOR DEMENTIA. ABOUT 30 PERCENT OF THOSE OVER 85 YEARS HAVE DEMENTIA.

THE RAPID AGEING OF THE POPULATION MEANS THAT THE NUMBER OF PEOPLE WITH DEMENTIA IN AUSTRALIA WILL ALSO INCREASE. BY 2020, JUST SEVEN YEARS AWAY THE NUMBER OF PEOPLE WITH DEMENTIA WILL REACH ALMOST 400,000. BY 2050 THERE WILL BE NEARLY 900,000 AUSTRALIANS WITH DEMENTIA. JUST IMAGINE, THAT IS THE EQUIVALENT OF A CITY TWICE THE SIZE OF NEWCASTLE.

THE DIRECT COST OF DEMENTIA TO THE HEALTH CARE SYSTEM IS ALREADY NEARLY \$5 BILLION.

THE ALZHEIMER'S AUSTRALIA FIGHT DEMENTIA ELECTION CAMPAIGN DOCUMENT HIGHLIGHTS THE PRIORITIES THAT HAVE BEEN SET OUT BY PEOPLE WITH DEMENTIA AND THEIR FAMILY CARERS. IT CAN BE FOUND AT CAMPAIGN.FIGHTDEMENTIA.ORG.AU

THERE ARE THREE ISSUES WHICH ARE CRITICAL FOR PEOPLE LIVING WITH DEMENTIA OF ALL AGES.

FIRSTLY, ACCESS TO CARE AND SUPPORT.

CONSUMERS WANT GREATER FLEXIBILITY, CHOICE AND SUPPORT TO CONTINUE TO LIVE IN THE COMMUNITY.

TO ACHIEVE THESE GOALS, THE INCOMING GOVERNMENT WILL NEED TO BEGIN A PROCESS OF TRANSITIONING FROM THE HIGHLY REGULATED RATIONING SYSTEM IN PLACE NOW TO A MARKET BASED SYSTEM WHICH RESPONDS MORE FREELY TO CONSUMER NEEDS.

WE NEED A COMMITMENT TO THE EXPANSION OF COMMUNITY CARE AND IN PARTICULAR TO THE NUMBER OF COMMUNITY CARE PACKAGES AVAILABLE TO THOSE WITH HIGHER CARE NEEDS. THIS IS PARTICULARLY IMPORTANT FOR OLDER PEOPLE WHO LIVE ALONE OR WHO HAVE LIMITED ACCESS TO INFORMAL CARER SUPPORT.

ONLY IN THAT WAY WILL OLDER PEOPLE AND THOSE WITH DEMENTIA HAVE A REAL ALTERNATIVE TO RESIDENTIAL HIGH CARE.

AS WELL AS INCREASING THE SUPPLY OF HIGH-LEVEL COMMUNITY PACKAGES, A CRITICAL ELEMENT IN ASSISTING PEOPLE WITH DEMENTIA TO LIVE IN THE COMMUNITY IS THE PROVISION OF DEMENTIA SPECIFIC RESPITE CARE.

WE PROPOSE A TRIAL OF CASHING OUT FOR RESPITE CARE WHICH WOULD ENABLE CONSUMERS TO ARRANGE SERVICES THEMSELVES. THIS WOULD BE A GOOD TEST TO SEE HOW INDIVIDUALISED FUNDING MIGHT WORK IN AGED CARE.

THIS APPROACH IS PARTICULARLY IMPORTANT FOR PEOPLE FROM REGIONAL AND RURAL AREAS WHO MAY HAVE DIFFICULTY GETTING ACCESS TO SERVICES THAT MEET THEIR NEEDS.

WE WOULD ALSO LIKE PEOPLE WITH DEMENTIA OF ALL AGES TO HAVE ACCESS TO KEY WORKERS SO THAT THEY ARE BETTER ABLE TO NAVIGATE THE CARE SYSTEM AND GET THE ADVICE THEY NEED. CURRENTLY THIS KIND OF SUPPORT THROUGH KEY WORKERS IS ONLY AVAILABLE TO THOSE LIVING WITH YOUNGER ONSET DEMENTIA.

THE SECOND MAJOR ISSUE FOR CONSUMERS IS QUALITY IN RESIDENTIAL CARE.

MANY OF YOU WILL HAVE SEEN THE DISTURBING REPORTS ON LATELINE OVER THE PAST 12 MONTHS ON INSTANCES OF POOR CARE IN RESIDENTIAL CARE FACILITIES.

AND WHILE WE RECOGNISE THAT THESE STORIES DO NOT REFLECT THE NORM, THEY DO HIGHLIGHT THE FACT THAT THE QUALITY OF CARE IS VARIABLE, AND IN SOME CASES NOT UP TO THE STANDARD THAT ANYBODY HERE WOULD EXPECT FOR THEMSELVES OR THEIR LOVED ONES.

FOR THIS REASON ALZHEIMER'S AUSTRALIA IS CALLING FOR ZERO TOLERANCE OF POOR QUALITY CARE AND VIOLATIONS OF BASIC HUMAN RIGHTS. IN PARTICULAR, WE NEED BETTER STRUCTURES IN PLACE TO MONITOR THE QUALITY OF CARE, TO ADVOCATE FOR CONSUMERS, TO MAKE OUTCOMES TRANSPARENT, AND TO PROVIDE REMEDIAL ACTION QUICKLY WHEN VIOLATION OF PEOPLE'S HUMAN RIGHTS OCCUR.

AND OF COURSE WE NEED TO INVEST IN THE TRAINING OF AGED CARE STAFF AND TO HAVE A COST OF CARE STUDY IN RESIDENTIAL CARE TO ENSURE FUNDING IS ADEQUATE FOR THE PROVISION OF QUALITY CARE.

AFTER MANY YEARS OF THE ACCREDITATION AND STANDARDS AGENCY BEING IN PLACE AND A PROMISE TO CONSUMERS THAT THE BAD APPLES WOULD BE WEEDED OUT, IT SEEMS SOME BAD APPLES ARE STILL THERE.

THE FINAL PRIORITY IS FUNDING FOR DEMENTIA RESEARCH.

THERE CAN BE NO HOPE FOR THE FUTURE WITHOUT INVESTMENT IN DEMENTIA RESEARCH. WE NEED \$200 MILLION ADDITIONAL FUNDING OVER THE NEXT FIVE YEARS TO:

1. BUILD CAPACITY IN DEMENTIA RESEARCH
2. TO FUND NEW RESEARCH PROJECTS THAT ARE DIRECTED AT CAUSE, CARE AND PREVENTION OF DEMENTIA.

3. TO ENSURE THAT AUSTRALIAN RESEARCHERS HAVE ACCESS TO TOP QUALITY INFRASTRUCTURE TO WORK TOWARDS A WORLD WITHOUT DEMENTIA.

AN INVESTMENT OF \$200 MILLION OVER 5 YEARS THIS WOULD REPRESENT A TOTAL DEMENTIA INVESTMENT OF LESS THAN 1.5% OF THE COST OF DEMENTIA TO THE HEALTH CARE SYSTEM – AND THAT DOES NOT INCLUDE THE COST TO FAMILY CARERS.

ALZHEIMER'S AUSTRALIA IS PLEASED WITH THE PROGRESS THAT HAS BEEN MADE IN PUTTING THE AGED CARE REFORMS INTO PLACE THROUGH *LIVING LONGER.LIVING BETTER.* – ESPECIALLY THE RECOGNITION OF THE EXTRA COSTS OF DEMENTIA CARE AND THE FIRST MEASURES IN NATIONAL AUSTRALIAN HEALTH POLICY TO TACKLE TIMELY DIAGNOSIS, DEMENTIA CARE IN HOSPITALS AND THE WORLDS FIRST PUBLICLY FUNDED DEMENTIA RISK REDUCTION PROGRAM.

WE ARE ONLY AT THE BEGINNING OF THE IMPLEMENTATION OF THE AGED CARE REFORMS WHICH ON ANY REALISTIC ASSESSMENT WILL TAKE FIVE TO TEN YEARS TO WORK THROUGH. THESE REFORMS WILL INVOLVE THE INTRODUCTION OF QUALITY CARE INDICATORS, THE DEVELOPMENT OF FAIR USER CHARGES AND GREATER FLEXIBILITY AND SUPPLY OF SERVICES.

THESE ARE REFORMS THAT WILL BENEFIT ALL AUSTRALIANS INCLUDING PEOPLE FROM CULTURALLY AND LINGUISTICALLY DIVERSE BACKGROUNDS, INDIGENOUS PEOPLE, THE HOMELESS AND THE LGBTI COMMUNITIES.

THE NEW GOVERNMENT WILL NEED TO ENSURE THAT THE INTERFACE BETWEEN AGED CARE AND DISABILITYCARE WORKS SEAMLESSLY.

THE DISABILITY AND AGED CARE REFORMS CAN LEARN MUCH FROM THE OTHER, FOR EXAMPLE HOW THE MARKET RESPONDS TO INDIVIDUALISED

FUNDING, MANAGING THE BALANCE BETWEEN CHOICE AND RISK AND THE MONITORING OF THE QUALITY OF THE SERVICES PROVIDED.

AT LONG LAST THERE IS THE OPPORTUNITY FOR MAJOR REFORM OF AUSTRALIA'S AGED CARE SYSTEM AND TO TACKLE DEMENTIA. IT MERITS A HIGH PRIORITY AND COMMITMENT FROM ALL THE MAJOR PARTIES AND MINOR PARTIES.