

WORLD ALZHEIMER'S MONTH DEMENTIA ALLIANCE INTERNATIONAL
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DEMENTIA: GLOBAL PERSPECTIVES AND PRIORITIES

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CHAIR ADI

THANK YOU FOR THE OPPORTUNITY TO TALK WITH YOU IN WORLD ALZHEIMER'S MONTH. **SLIDE 2** A LOT IS HAPPENING DURING THE MONTH AND I WOULD BE INTERESTED IN YOUR VIEWS ON THE THEME AND THE ACTIVITIES.

IT GAVE ME GREAT PLEASURE DURING THE LAST HALF OF 2015 TO ADVOCATE FOR ADI TO ENTER A PARTNERSHIP WITH DAI RATHER THAN ESTABLISH AN ADI GROUP.

I HAVE BEEN AROUND LONG ENOUGH TO KNOW THAT, HOWEVER WELL-INTENTIONED, GROUPS THAT ARE SET UP WITHIN ORGANISATIONS ARE SUBJECT TO CONTROL WHICH OVER TIME LEAD TO FRUSTRATION AND TENSION

EQUALLY IT IS IMPORTANT NOT ONLY THAT DAI HAS POSITIONS OF ITS OWN BUT THAT ADI TOO HAS THE CAPACITY TO PURSUE ISSUES IN THE WAY IT THINK BEST, FOR EXAMPLE IN RESPECT OF THE BUSINESS MODEL FOR CONFERENCES OR THE MOST EFFECTIVE WAY TO PROSECUTE GLOBAL ADVOCACY.

SO PARTNERSHIP BASED ON MUTUAL RESPECT IS THE BEST WAY FORWARD AND SLOWLY I THINK WE ARE DEVELOPING A PLATFORM FROM WHICH PEOPLE WITH DEMENTIA WILL BENEFIT

A START HAS BEEN MADE. DAI HAS DETERMINED PROJECTS WHICH ARE A PRIORITY FOR SUPPORT BY ADI AND ESTABLISHED A BASIS TO DEVELOP CONFERENCES RUN BY PEOPLE WITH DEMENTIA THEMSELVES, STARTING WITH THE REGIONAL CONFERENCE IN NEW ZEALAND NEXT YEAR

I DETECT NOTHING BUT SUPPORT WITHIN THE BOARD AND THE ADI OFFICE FOR THE PARTNERSHIP AND CLEARLY THERE ARE ALZHEIMER ORGANISATIONS LIKE ALZHEIMER'S SCOTLAND AND NEW ZEALAND WHO HAVE A DEEP COMMITMENT TO THE PRACTICAL IMPLEMENTATION OF HUMAN RIGHTS FOR PEOPLE WITH DEMENTIA.

I WANTED TO START WHAT I SAY TO YOU IN THAT WAY BECAUSE IT IS IMPORTANT THAT YOU UNDERSTAND ADI WELCOMES THE POTENTIAL OF DAI TO GROW AS A FORCE IN ADVOCATING FOR THE RIGHTS OF PEOPLE WITH DEMENTIA. I DOUBT I CAN UNDERSTAND THE MANY FRUSTRATIONS MANY IF NOT ALL YOU FACE IN YOUR DAY TO DAY LIFE BUT IT IMPORTANT YOU UNDERSTAND THAT ADI REGARDS DAI AS AN EQUAL PARTNER.

SLIDE 3 WHAT I WILL TALK ABOUT TODAY IS:

- THE 2015 WORLD ALZHEIMER'S REPORT ***THE GLOBAL IMPACT OF DEMENTIA***
- THE OPPORTUNITIES FOR ADVOCACY OVER THE NEXT 12 MONTHS

- THE PRIORITIES THAT ADI WILL BE SEEKING TO INCLUDE IN A GLOBAL CALL FOR ACTION AT THE WHO NEXT YEAR
- THE DRIVERS FOR CHANGE

SLIDE 4 I AM NOT GOING TO TEST YOU ON THE 80 PAGES OF THE 2016 REPORT BUT I DO HOPE YOU HAVE HAD AN OPPORTUNITY TO LOOK AT IT. IT IS A WELL RESEARCHED DOCUMENT THAT PROVIDES AN EXCELLENT BASIS FOR POLITICAL ADVOCACY AT THE GLOBAL LEVEL. IT IS PROBABLY AS WEARYING FOR YOU AS IT IS FOR ME TO PLAY THE NUMBERS GAME BUT IT IS THE IMPACT OF DEMENTIA ON HEALTH AND CARE SYSTEMS THAT WE HAVE TO GET ACROSS AS WELL AS THE HUMAN COST.

THE KEY FINDINGS ARE THAT THERE HAS BEEN A 12-13 % INCREASE IN THE GLOBAL ESTIMATES OF PEOPLE WITH LIVING WITH DEMENTIA SINCE THE 2009 REPORT WITH MUCH OF THE INCREASE TAKING PLACE IN LOW AND MIDDLE INCOME COUNTRIES. THE NUMBERS ARE EXTRAORDINARY

- **SLIDE 5** 46.8 MILLION PEOPLE WORLD WIDE ARE LIVING WITH DEMENTIA IN 2015. THIS NUMBER WILL GROW TO 131.5 MILLION BY 2050
- **SLIDE 6** THERE WILL 9.9 MILLION NEW CASES OF DEMENTIA IN 2015
- **SLIDE 7** THE TOTAL ESTIMATED COST OF DEMENTIA IS US \$813 BILLION, A FIGURE PROJECTED TO INCREASE BY 2018 TO US \$! TRILLION – THAT IS A NUMBER WITH TWELVE ZEROS – A BIT OUTSIDE MY COMPREHENSION!

SLIDE 8 THERE IS A GREAT DEAL OF ANALYSIS IN THE REPORT BUT TWO ISSUES ARE WORTH A SPECIAL MENTION

FIRST, THE AUTHORS ASSUME IN THE PROJECTED FIGURES THAT THE PREVALENCE OF DEMENTIA WILL NOT VARY OVER TIME AND THAT IT IS THE AGEING OF THE POPULATION THAT ALONE DRIVES THE PROJECTED INCREASES. IN REALITY OF COURSE THE PREVALENCE COULD BE AFFECTED BOTH BY A CHANGING NUMBER OF NEW CASES AND LENGTH OF LIFE.

FOR EXAMPLE THE TREND IN HIGH INCOME COUNTRIES TO LESS SMOKING, LOWER CHOLESTEROL, LOWER BLOOD PRESSURE AND PHYSICAL EXERCISE MIGHT REDUCE RATES. ON THE OTHER HAND THE PREVALENCE OF DIABETES AND OBESITY IS INCREASING.

IN LOW AND MIDDLE INCOME COUNTRIES THE RATES MAY MOVE ADVERSELY AS TRENDS IN CARDIOVASCULAR DISEASE MOVE IN AN ADVERSE DIRECTION.

THE RESEARCHERS CONCLUDE AT THIS STAGE THAT THE RESEARCH BASE IS NOT SUFFICIENT TO MAKE CHANGES IN RISK FACTOR PROFILES

SECOND, THE AUTHORS NOTE WITH CONCERN THAT THE REVISED GLOBAL BURDEN OF DISEASE ESTIMATES FAIL TO CAPTURE THE FULL IMPACT OF CHRONIC DISEASES AND ESPECIALLY DEMENTIA ON DISABILITY, NEEDS FOR CARE AND ATTENDANT SOCIETAL COSTS. THIS FAILURE IS IMPORTANT BECAUSE IT MAKES GLOBAL ESTIMATES AN UNRELIABLE BASIS FOR PRIORITISING RESEARCH, PREVENTION AND HEALTH OR SOCIAL CARE AMONG OLDER PEOPLE.

I HOPE THE RPEORT IS HELPFUL IN YOUR ADVOCACY. WHILE SOME OF YOU MAY FEEL THE FIGURES CAN TRIVIALISE THE ISSUES I KNOW FIRST-HAND WHAT THE POLITICAL REACTION WAS IN AUSTRALIA TO THE US \$1 TRILLION FIGURE. SOUND BITES ARE IMPORTANT.

SO WHAT ARE THE OPPORTUNITIES FOR ADVOCACY?

WE CAN I THINK BE WELL PLEASED WITH THE INCREASED GLOBAL RECOGNITION OF DEMENTIA AS A HEALTH PRIORITY WHILE BEING REALISTIC ABOUT THE TIME IT WILL TAKE TO RESULT IN IMPROVEMENTS IN QUALITY OF LIFE FOR THOSE WITH DEMENTIA AND THEIR FAMILY CARERS.

AFTER ALL IT HAS TAKEN MANY YEARS FOR SOME HIGH INCOME COUNTRIES TO MAKE DEMENTIA A FOCUS FOR NATIONAL PLANNING OR ACTION.

I REMAIN OF THE VIEW THAT AT THE GLOBAL AND LOCAL LEVEL THE NEED IS FOR REVOLUTION AND NOT EVOLUTION IF WE ARE TO TACKLE STIGMA AND THE ENDURING VIEW THAT DEMENTIA IS AN INEVITABLE PART OF AGEING RATHER THAN A CHRONIC DISEASE.

SLIDE 9 SO WHAT ARE THE POSITIVES AT THE GLOBAL LEVEL?

FIRST, THE ESTABLISHMENT OF AN EVIDENCE BASE. THE WORK OF MARTIN PRINCE AND THE 10/66 RESEARCH GROUP TOGETHER WITH ADI IN PUBLISHING WORLD ALZHEIMER'S REPORTS HAVE ENSURED A BASIS FOR SHARING GLOBALLY KEY INFORMATION.

THE INFORMATION BASE IS MATCHED IN IMPORTANCE BY A CHANGE IN LANGUAGE THAT EMBRACES DEMENTIA AS A PUBLIC HEALTH ISSUE, DEMENTIA AS A CHRONIC DISEASE, THE LANGUAGE OF PREVENTION AND REHABILITATION AND THE RECOGNITION THAT DEMENTIA IS AS MUCH A SOCIAL AS MEDICAL ISSUE.

THE FIRST VICTORY IN ANY REVOLUTION IS TO HAVE OTHERS USE YOUR INFORMATION AND LANGUAGE. WE ARE NOT THERE YET BUT A GOOD START IS BEING MADE.

SLIDE 10 SECOND, THE MULTIPLICITY OF CHANNELS THROUGH WHICH TO PROSECUTE THE ISSUE OF DEMENTIA. TO MAKE THE POINT LET ME LIST THEM QUICKLY IN WHAT I PERCEIVE TO BE SOME ORDER OF IMPORTANCE

- THE WORLD HEALTH ORGANISATION AND THE RECENT MINISTERIAL DEMENTIA MEETING WHICH RESULTED IN A DECLARATION
- THE WORLD DEMENTIA COUNCIL ESTABLISHED AS A PLATFORM FOR GOVERNMENTS, INDUSTRY, NGOS AND PEOPLE WITH DEMENTIA TO SET THE AGENDA FOR TACKLING DEMENTIA
- THE PAN AMERICAN PACIFIC HEALTH ORGANISATION AND ITS WORK ON AN ACTION PLAN TO SUPPORT LOWER AND MIDDLE INCOME COUNTRIES IN THE REGION OF THE AMERICAS
- THE 2014 GLASGOW DECLARATION AND THE ADVOCACY OF ALZHEIMER'S EUROPE ON A EUROPEAN DEMENTIA STRATEGY
- THE WORK BEING DONE BY THE ORGANISATION FOR ECONOMIC COOPERATION AND DEVELOPMENT ON AGED CARE INCLUDING THE QUALITY OF CARE
- THE WORK OF THE NON COMMUNICABLE DISEASE ALLIANCE IN ESTABLISHING A BASIS FOR COOPERATION ON PREVENTION ACROSS THE MAJOR CHRONIC DISEASES
- THE GLOBAL ALZHEIMER'S AND DEMENTIA ACTION ALLIANCE FORMED IN RESPONSE TO THE G7 INITIATIVE BY INTERNATIONAL NGOS TO ENHANCE GLOBAL EFFORTS TO COMBAT STIGMA, EXCLUSION AND FEAR
- MECHANISMS TO IMPROVE ALL ASPECTS OF DRUG DEVELOPMENT
- INCLUSION OF DEMENTIA WITHIN THE CONVENTION ON THE RIGHTS OF PEOPLE WITH DISABILITIES (CPRD)

THE CRPD CONVENTION IS A WIDE-RANGING AND COMPLEX DOCUMENT BUT SOME OF THE PROVISIONS THAT RELATE TO DEMENTIA ARE

- ARTICLE 2 ON EQUAL RECOGNITION BEFORE THE LAW E.G. SUPPORTED DECISION MAKING THAT RESPECTS THE PERSON'S CAPACITY)
- ARTICLE 19 (ON LIVING INDEPENDENTLY AND BEING INCLUDED IN THE COMMUNITY AND,
- ARTICLES 24, 27, 28 AND 30 WHICH INCLUDE COMPREHENSIVE ACCESS TO SERVICES INCLUDING EDUCATION, WORK, PARTICIPATION IN RECREATIONAL AND SPORTING ACTIVITIES

THE BOARD OF ADI HAS ASKED THE CEO TO APPROACH ALZHEIMER'S SCOTLAND WITH A VIEW TO WORKING TOGETHER ON DEMENTIA AND HUMAN RIGHTS.

THE CHALLENGE WHICH I WILL COMEBACK TO LATER IS HOW TO SUSTAIN THIS INTEREST, AVOID DUPLICATION OF EFFORT AND ACHIEVE COORDINATION.

SLIDE 11 THIRD, THE INCREASING RECOGNITION OF DEMENTIA AS A PUBLIC HEALTH ISSUE AND WITH THAT THE POTENTIAL OF PREVENTION.

TWO OF THE MOST IMPORTANT CHANGES IN MESSAGING IN THE TIME I WAS CEO OF ALZHEIMER'S AUSTRALIA WERE THAT DEMENTIA IS NOT A NATURAL PART OF AGEING AND THAT IT MAYBE PREVENTABLE.

THIS OFFERS SOME HOPE OF ACTION WHILE THE LONG WAIT CONTINUES FOR MEDICAL TREATMENTS.

THE OTHER MESSAGE IS THAT DEMENTIA IS AS MUCH A SOCIAL AS A MEDICAL ISSUE – HENCE THE IMPORTANCE OF SOCIAL ACTION TO COMBAT STIGMA.

FOURTH, THE PRIORITY GIVEN AT THE GLOBAL LEVEL TO THE IMPORTANCE OF RESEARCH FUNDING IN ORDER TO IDENTIFY THOSE AT RISK OF DEMENTIA, TO FIND NEW TREATMENTS AND TO TRANSLATE RESEARCH INTO PRACTICE.

THE RESULT IS INCREASED RESEARCH FUNDING IN RECENT TIMES. HOWEVER, IT IS WELL BELOW WHAT IS REQUIRED IF IT IS TO BE TAKEN AS SERIOUSLY AS IS FOR EXAMPLE CANCER AND CARDIO VASCULAR MEDICAL RESEARCH.

BUT WHATEVER OUR DOUBTS THE COMMITMENT MADE BY THE THEN G8 TO FIND A CURE FOR DEMENTIA BY 2025 IT IS A USEFUL POLITICAL HOOK.

SO HAVING GOT TO THE POINT OF CAUTIOUS OPTIMISM ABOUT PROGRESS AT THE GLOBAL LEVEL OVER THE LAST 18 MONTHS IN GETTING DEMENTIA ON THE POLITICAL AGENDA I SUGGEST TWO KEY QUESTIONS REMAIN.

SO HOW DO WE FOCUS THE GLOBAL AGENDA?

SLIDE 12 I ASKED YOU ALL TO LOOK AT THE CALL TO ACTION IN PARAGRAPH 7.5 OF THE 2015 REPORT BECAUSE I BELIEVE IT SETS OUT IN SHORT SPACE WHAT ADI SHOULD BE SEEKING TO ADVOCATE FOR OVER THE NEXT 12 MONTHS.

THE ELEMENTS WE HAVE INCLUDED AS ELEMENTS FOR PLANNING FOR DEMENTIA AT THE GLOBAL AND COUNTRY LEVEL HAVE THE OBJECTIVE OF SUPPORTING THE PERSON WITH DEMENTIA TO STAY IN THE COMMUNITY FOR AS LONG AS POSSIBLE INCLUDE

- a) AWARENESS RAISING OF DEMENTIA
- b) CREATION OF DEMENTIA FRIENDLY COMMUNITIES THAT REDUCE STIGMA ASSOCIATED WITH THE DISEASE
- c) PROMOTION OF RISK REDUCTION MEASURES
- d) MEASURES TO IMPROVE DIAGNOSIS AND REDUCE THE AVERAGE LENGTH OF DIAGNOSIS

- e) SUPPORT FOR FAMILY CARERS INCLUDING THROUGH INFORMATION, SOCIAL SUPPORT , RESPITE AND COUNSELLING
- f) ACCESS TO LONG TERM COMMUNITY AND RESIDENTIAL DEMENTIA CARE SERVICES AND TO ENHANCED CARE FOR PEOPLE DEMENTIA IN HOSPITALS
- g) **SLIDE 13** A COMMITMENT TO PERSON CENTRED CARE AND TO CARE THAT MINIMISES THE USE OF MEDICAL AND PHYSICAL RESTRAINT
- h) WORKFORCE STRATEGIES INCLUDING TRAINING
- i) THE USE OF TECHNOLOGY TO ASSIST THE PERSON WITH DEMENTIA IN THE HOME AND TO EXTEND SERVICE REACH IN RURAL AREAS
- j) RECOGNITION THAT DEMENTIA DESERVE GOOD QUALITY END OF LIFE CARE WITH RESPECT TO THEIR DIGNITY AND PERSONAL WISHES

THERE IS OF COURSE A RECOGNITION TOO OF THE NEED FOR INCREASED DEMENTIA RESEARCH FUNDING.

SLIDE 14 LET ME MAKE THREE OBSERVATIONS ABOUT HOW WE SHOULD APPROACH ADVOCACY

FIRST TO EMPHASISE THE NEED FOR DEMENTIA PLANS – PREFEREABLY WITH FUNDING BUT EVEN WITHOUT THEY ARE A FIRST STEP IN RECOGNITION OF THE ISSUES. ADI EXPECTS 25 COUNTRIES TO HAVE PLANS BY THE END OF THISYEAR.

SECOND TO INSIST ON SYSTEMIC CHANGE THAT TOUCHES ALL PARTS OF THE HEALTH AND CARE AND SOCIAL SUPPORT. WE ARE NOT GOING TO SUCCESSFULLY TACKLE DEMENTIA FOR EXAMPLE IN RESPECT OF TIMELY DIAGNOSIS AND DEMENTIA IN HOSPITALS IF WE DO NOT TAKE A SYSTEMS WIDE APPROACH. IT IS ONLY BY CHANGES SYSTEMS THAT PEOPLE WITH DEMENTIA WILL BE ABLE TO EXERCISE THEIR RIGHT TO CARE AND SUPPORT AS ALZHEIMER'S SCOTLAND ARE DEMONSTRATING

THIRD TO INSIST THAT THE MISTAKES OF HIGH INCOME COUNTRIES ARE NOT REPLICATED IN LOW AND MIDDLE INCOME COUNTRIES BY GIVING PRIORITY TO RESIDENTIAL CARE AT THE EXPENSE OF COMMUNITY BASED CARE AND SUPPORT THAT ENABLES THE PERSON WITH DEMENTIA TO STAY IN THE COMMUNITY FOR AS LONG AS POSSIBLE.

I WOULD WELCOME YOUR RESPONSE IN DISCUSSION THE PRIORITIES THAT HAVE BEEN ADVANCED BY ADI FOR A CALL TO ACTION

SLIDE 15 SO FINALLY WHAT ARE THE DRIVERS OF CHANGE?

FIRST, WE NEED POLITICAL LEADERSHIP OF THE KIND UK PRIME MINISTER CAMERON HAS DELIVERED THROUGH THE G7 GLOBAL DEMENTIA CHALLENGE. BUT IT HAS BEEN CIVIL SOCIETY THAT HAS HELPED SHAPE THAT INITIATIVE BEYOND RESEARCH AND STREAMLINING THE REGULATION OF MEDICINES TO INCLUDE PEOPLE WITH DEMENTIA, DEMENTIA CARE AND PREVENTION.

IF WE WANT FUNDING AND ACTION WE NEED TO BROADEN OUT THE POLITICAL COUNTRY SUPPORT FOR THE GLOBAL CHALLENGE BEYOND THE UK. THIS IS THE MISSING PIECE OF THE PUZZLE. WHAT OTHER COUNTRIES WILL STEP UP TO THE PLATE?

THE 2015 REPORT FLOATS THE POSSIBILITY OF A TRANSFER OF POLITICAL LEADERSHIP TO THE G20 GROUP OF NATIONS ASSUMING CONTINUED COMMITMENT AND ENGAGEMENT OF THE G7 GROUP OF NATIONS. THIS IS CRITICAL IN MY VIEW AS THE G20 ACCOUNT FOR ABOUT 80% OF THE WORLD'S POPULATION OF PEOPLE WITH DEMENTIA

SECOND, AMONG THE INTERNATIONAL ACTORS THE WORLD HEALTH ORGANISATION IS KEY. THE WORLD HEALTH ORGANISATION IS POSITIONED TO DO WHAT NO OTHER CAN DO IN DRAWING TOGETHER MEMBER COUNTRIES TO DISCUSS AND PRIORITISE ACTION IN PUBLIC HEALTH POLICY. THE RECENT MINISTERIAL COUNCIL IS EVIDENCE OF THAT AND MADE A GREAT START IN PRODUCING A WELL WORDED DECLARATION – BUT THAT WAS WHAT IT WAS, WELL WORDED WITH NO HINT OF ACTION.

SO ADI THROUGH OUR CEO IS WORKING WITH GOVERNMENTS FOR A RESOLUTION IN 2016 AT THE WORLD HEALTH ASSEMBLY TO LAY THE BASIS FOR A CALL TO ACTION.

WE WILL GET THIS COMMITMENT ONLY IF WE HAVE COUNTRIES TO SUPPORT DEMENTIA AS A HEALTH PRIORITY.

THIRD, ON ANY GLOBAL SCENARIO WE NEED A STRONG ADI AND STRONG ALZHEIMER'S ORGANISATIONS. IT IS THE EMOTIONAL ENERGY AND COMMITMENT OF PEOPLE WITH DEMENTIA AND THEIR FAMILY CARERS THAT HAVE CREATED AWARENESS OF DEMENTIA AND THE NEED FOR REVOLUTION OVER DECADES.

AS THE CHAIR OF ADI I CAN SAY IT IS A MIRACLE THAT ADI HAS MAINTAINED SUCH A FORCEFUL PRESENCE AT THE GLOBAL LEVEL OVER THE LAST 18 MONTHS WITH SUCH LIMITED RESOURCES. AND THESE RESOURCES ARE ALSO REQUIRED TO SUPPORT NEW AND EMERGING ALZHEIMER'S ORGANISATIONS IN LOW AND MIDDLE INCOME COUNTRIES.

THE WORK OF ADI NEEDS TO BE SUPPLEMENTED BY NEW PARTNERSHIPS THROUGH THE WORK OF THE GLOBAL ALZHEIMER'S AND DEMENTIA ALLIANCE AND ALZHEIMER'S ORGANISATIONS.

INDIVIDUAL ALZHEIMER'S ORGANISATIONS CAN PLAY A ROLE WAY BEYOND THEIR BORDERS. FOR EXAMPLE, AS ALZHEIMER'S AUSTRALIA DID BY ADVOCATING FOR DEMENTIA TO BE A PRIORITY ON THE BASIS OF ECONOMIC AND SOCIAL ANALYSIS, AS ALZHEIMER'S SCOTLAND HAS DONE IN CONSUMER ADVOCACY AND MORE RECENTLY IN MANDATING POST DIAGNOSTIC SUPPORT AND AS JAPAN AND THE UK HAVE DONE MORE RECENTLY IN IMPLEMENTING DEMENTIA FRIENDLY COMMUNITIES AND DEMENTIA FRIENDS.

THERE ARE NO PROMISES IN ADVOCACY ONLY HARD WORK AND COMMITMENT. MY DREAM IN THE NEXT 12 MONTHS IS TO ACHIEVE IN THE GLOBAL ADVOCACY OF ADI A CALL FOR ACTION IN THE WHO AND THE ATTENTION OF THE G20.

THANK YOU AGAIN FOR THE OPPORTUNITY TO SPEAK TO YOU AND I LOOK FORWARD TO SOME DISCUSSION NOW **SLIDE16**