

ALZHEIMER'S DISEASE INTERNATIONAL CONFERENCE
PERTH 2015

DEMENTIA PAST, PRESENT AND FUTURE

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ALZHEIMER'S DISEASE INTERNATIONAL

I AM DELIGHTED TO HAVE THE OPPORTUNITY TO GIVE A POLICY AND POLITICAL PERSPECTIVE ON DEMENTIA PAST, PRESENT AND FUTURE OVER THE LAST 30 YEARS.

I SUGGEST THE GAME CHANGERS OVER THE LAST 30 YEARS ARE CIVIL SOCIETY THROUGH ALZHEIMER'S ORGANISATIONS, A GREATER UNDERSTANDING OF HOW TO PROVIDE GOOD DEMENTIA SUPPORT AND CARE, THE RECOGNITION OF DEMENTIA AS A CHRONIC DISEASE AND THE POTENTIAL OF RISK REDUCTION AND LASTLY, THE RECENT FOCUS ON CREATING DEMENTIA FRIENDLY SOCIETIES.

THIRTY YEARS IN 1985 AGO I CHAIRED A REVIEW OF NURSING HOMES AND HOSTELS FOR THE THEN AUSTRALIAN GOVERNMENT. DEMENTIA WAS JUST ABOUT ON OUR RADAR – WE KNEW ABOUT PREVALENCE RATES AND THAT ABOUT 50 PER CENT OF RESIDENTS IN NURSING HOMES HAD DEMENTIA.

MY REVIEW RECOMMENDED AN INNOVATIVE PROGRAM FOR THE CARE OF PEOPLE WITH DEMENTIA, PEOPLE FROM ETHNIC COMMUNITIES, ABORIGINES AND ISOLATED RURAL DWELLERS. THAT RECOMMENDATION AND ALL THE OTHERS WERE ACCEPTED BY THE GOVERNMENT.

THE POSITIVE INDUSTRY RESPONSE TO DEMENTIA GRANTS CONVINCED ME THAT DESIGNATED FUNDING IS NECESSARY TO ACHIEVE APPROPRIATE DEMENTIA CARE AND TO RECOGNISE THE COSTS INVOLVED.

WHEN I BECAME CEO OF ALZHEIMER'S AUSTRALIA IN 2000 I COULD SEE THAT NOT MUCH HAD CHANGED IN 15 YEARS OF PUBLIC POLICY IN RESPECT OF DEMENTIA. GOVERNMENT POLICY WAS FOUNDED ON MAINSTREAMING DEMENTIA. THERE WAS LITTLE OR NO SPECIAL PROVISION AND NO RECOGNITION OF DEMENTIA AS A PUBLIC HEALTH ISSUE ALONGSIDE OTHER NATIONAL HEALTH PRIORITIES SUCH AS CANCER AND HEART.

THE SEA CHANGE IN AUSTRALIA STARTED FROM AROUND 2000 AND THE PRECONDITIONS HAVE BEEN THE SELF ADVOCACY OF PEOPLE WITH DEMENTIA AND THE STRONG EVIDENCE BASE FOR ACTION ESTABLISHED

BY ALZHEIMER'S AUSTRALIA. A PATTERN REPLICATED ACROSS DEVELOPING COUNTRIES.

IN 2010 I PRESENTED A PAPER AT THE HAMMOND CONFERENCE DEMENTIA: EVOLUTION OR REVOLUTION. I CONCLUDED THAT ONLY A REVOLUTION COULD DELIVER ON ACCESS TO BETTER SERVICES, BETTER PRIMARY CARE, AND ON A HEALTH POLICY TO REDUCE FUTURE NUMBERS OF PEOPLE WITH DEMENTIA THROUGH RESEARCH AND RISK REDUCTION.

REVOLUTION IS NECESSARY TO REMOVE THE PERVASIVE NEGATIVE STERO-TYPING, STIGMA AND SOCIAL ISOLATION THAT RESULTS FROM A DIAGNOSIS OF DEMENTIA AND THE FAILURE OF HEALTH POLICY TO EMBRACE DEMENTIA AS A CHRONIC DISEASE.

AT THE 2012 ADI CONFERENCE IN LONDON I SUGGESTED IN MY ADDRESS THAT ALZHEIMER'S ORGANISATIONS HAVE TO BE THE AGENTS OF CHANGE. THE GREAT WORK OF ADI AND MANY ALZHEIMER'S ASSOCIATIONS OVER THE LAST DECADE CONVINCES ME MORE THAN EVER THAT IT IS CIVIL SOCIETY THAT HAS TO DRIVE THE REVOLUTION.

I BELIEVE THE STRONGER ADVOCACY OF ALZHEIMER'S AUSTRALIA CONTRIBUTED SIGNIFICANTLY TO THE OUTCOME OF THE 2012 AGED CARE REFORMS. THE REFORMS INCLUDED A \$270 MILLION PACKAGE TO TACKLE DEMENTIA AND A COMMITMENT TO MAKE DEMENTIA A NATIONAL HEALTH PRIORITY. THERE WAS FUNDING FOR TIMELY DIAGNOSIS, DEMENTIA SUPPLEMENTS, DEMENTIA AND ACUTE CARE, DEMENTIA RISK REDUCTION AND YOUNGER ONSET DEMENTIA KEYWORKERS.

THERE IS NOW ADDITIONAL FUNDING OF \$200M FOR DEMENTIA RESEARCH

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.

IT IS THE EMOTIONAL ENERGY AND COMMITMENT OF PEOPLE WITH DEMENTIA AND THEIR FAMILY CARERS OVER THE LAST 30 YEARS THAT HAVE CREATED AWARENESS OF DEMENTIA AND THE NEED FOR REVOLUTION.

IF I AM RIGHT THAT THE LESSONS OF THE PAST ARGUE FOR REVOLUTION AND THE ROLE OF CIVIL SOCIETY AND ALZHEIMER ASSOCIATIONS THE QUESTION IS HOW TO SET AN AGENDA FOR THE FUTURE. LET ME SUGGEST THREE PRIORITIES

FIRST, TO TACKLE STIGMA THROUGH SOCIAL ACTION.

DISABILITY ADVOCATES HAVE SHOWN US THE WAY. WE NEED TO ENSURE THAT THE RIGHTS OF PEOPLE WITH DEMENTIA OF ALL AGES ARE PROTECTED AND TO ENSURE THAT THEY HAVE THE OPPORTUNITY TO PARTICIPATE IN SOCIETY AS WELL HAVE A PURPOSE IN LIFE – WHICH IS WHAT WE ALL SEEK IN OUR DIFFERENT WAYS.

THE STRATEGIES TO ACHIEVE THIS WOULD EACH REQUIRE A PLENARY SESSION AND SOME ARE HIGHLIGHTED AT THIS CONFERENCE.

THEY INCLUDE

- CREATING DEMENTIA FRIENDLY SOCIETIES
- BUILDING WORLDWIDE ON THE APPROACH OF JAPAN AND THE UK IN PROMOTING DEMENTIA CHAMPIONS
- SUPPORTING THE WORK OF THE UNITED NATIONS IN DEVELOPING A CHARTER ON THE RIGHTS OF OLDER PEOPLE
- THE WORK OF THE WORLD HEALTH ORGANISATION ON HEALTHY AGEING
- PROTECTING THE RIGHTS OF YOUNGER PEOPLE THROUGH THE UN CHARTER ON THE RIGHTS OF PEOPLE WITH DISABILITIES
- ADVOCATING FOR CONSUMER DIRECTED MODELS OF CARE

AFTER ESTABLISHING A GOOD LEVEL OF AWARENESS, SOCIAL ENGAGEMENT AND LEGAL FRAMEWORKS ARE CRITICAL ELEMENTS TO CHANGING CULTURES AND THE STIGMA THAT ATTACHES TO DEMENTIA

SECOND TO ESTABLISH DEMENTIA AS A PRIORITY THROUGH NATIONAL ACTION PLANS IN COUNTRIES AROUND THE WORLD. PLANS THAT DESIRABLY INCLUDE AWARENESS AND INFORMATION, TIMELY DIAGNOSIS, COMMUNITY AND RESIDENTIAL CARE, REHABILITATION, DEMENTIA AND RISK REDUCTION, ACUTE CARE AND RESEARCH.

A TALL ORDER? WELL 20 ARE IN PLACE WITH VARYING DEGREES OF COMPREHENSIVENESS. AND BY THE END OF THE YEAR ADI IS HOPING THERE WILL BE AT LEAST 25 PLANS INCLUDING ONE FOR THE PAN AMERICAN HEALTH ORGANISATION, THE REGIONAL WHO ORGANISATION IN THE AMERICAS

SOME PLANS LIKE THOSE OF AUSTRALIA, FRANCE, THE NETHERLANDS, THE UK, AND SOUTH KOREA HAVE FUNDING FOR DEMENTIA CARE AND RESEARCH. AND REMEMBER THAT DEMENTIA RESEARCH DESPITE RECENT INCREASES IN FUNDING REMAINS GROSSLY UNDERFUNDED IN RELATION TO CANCER AND CARDIO-VASCULAR DISEASE.

BUT WHETHER PLANS HAVE FUNDING ATTACHED OR NOT THEY ARE THE PRE-CONDITION FOR POLITICAL AWARENESS AND FUTURE ACTION.

ADI WILL CONTINUE TO SUPPORT THE DEVELOPMENT OF PLANS BY UPDATING INFORMATION ON WHAT IS HAPPENING AROUND THE WORLD, PROVIDING TECHNICAL SUPPORT AND RUNNING ALZHEIMER'S UNIVERSITIES.

IT IS NOT ENOUGH OF COURSE TO RELY ON PLANS. WE MUST ALSO BE INCREASINGLY EFFECTIVE IN HOW WE COMMUNICATE OUR MESSAGES. AS PART OF THAT WE HAVE TO COMMIT TO TELLING WITH EVER GREATER PASSION THE STORIES OF PEOPLE WITH DEMENTIA AND THEIR FAMILY CARERS AND SUPPORTERS.

A QUOTE FROM A PERSON WITH DEMENTIA IN RESPONSE TO AN ALZHEIMER'S AUSTRALIA SURVEY LAST YEAR SAYS IT ALL – "SOMETIMES MY SOCIAL DEATH MAKES ME MORE SAD THAN THE CHANGES TO MY BRAIN AND THE LOSS OF MY MEMORIES. IT MAKES ME SO ANGRY. I JUST WANT TO

BE COUNTED AS A PERSON AGAIN". THOUGHTS LIKE THAT ARE NEVER TO BE FORGOTTEN.

I BELIEVE TOO THAT DEMENTIA AND RISK REDUCTION IS IMPORTANT TO CONVEYING A POSITIVE MESSAGE UNTIL SUCH TIME AS RESEARCH PROVIDES THE BASIS FOR MODIFYING THE PROGRESSION OF THE DISEASE.

IF ALL THAT IS NOT ENOUGH, ADI NEEDS TO ENSURE A FOCUS IN ITS WORK ON THE QUALITY OF DEMENTIA CARE. THE ORGANISATION FOR ECONOMIC COOPERATION AND DEVELOPMENT RIGHTLY EMPHASISED ITS CONCERN ABOUT THIS AT THE WHO MINISTERS DEMENTIA MEETING AND INDICATED ITS INTENTION TO DO IMPORTANT WORK IN THAT AREA.

THIRD FOR ADI TO GIVE PRIORITY TO SUPPORTING ALZHEIMER'S ASSOCIATIONS IN LOW AND MIDDLE INCOME COUNTRIES AND TO ESTABLISH ORGANISATIONS WHERE THEY CURRENTLY DO NOT EXIST.

IT IS HEART BREAKING TO VISIT COUNTRIES THAT HAVE VIRTUALLY NO OR VERY LOW AWARENESS OF DEMENTIA, FEW SERVICES AND ENTRENCHED NEGATIVE ATTITUDES TO DEMENTIA. MY OWN PERSONAL COMMITMENT WILL BE TO ASSIST THOSE ASSOCIATIONS WHO SEEK HELP IN ADVOCATING TO THEIR NATIONAL GOVERNMENTS AND AGENCIES

HALF OF THE EIGHTY COUNTRIES REPRESENTED AT THE WHO MINISTERIAL CONFERENCE ON GLOBAL ACTION AGAINST DEMENTIA WERE LOW AND MIDDLE INCOME COUNTRIES. 10 LOW AND MIDDLE INCOME COUNTRIES SPOKE ABOUT DEMENTIA. TOGO AND MOZAMBIQUE TALKED ABOUT WITCHCRAFT AND THE HARM CAUSED TO PEOPLE WITH DEMENTIA, WHILE CHINA TALKED ABOUT AWARENESS AND TRAINING AND THE HELP THEY NEED FROM THE MEDIA OTHERS.

AGAIN THERE ARE MULTIPLE STRATEGIES INCLUDING SEEKING SUPPORT FROM DEVELOPMENT AGENCIES, WORKING TO PARTNER ADI WITH OTHER INTERNATIONAL ORGANISATIONS SUCH AS HELPAGE INTERNATIONAL AND THE WORLD COUNCIL OF CHURCHES. AS A RESULT OF THE GLOBAL INITIATIVE MANY OF THESE ORGANISATIONS ARE BEING BROUGHT

TOGETHER THROUGH THE GLOBAL ALZHEIMER'S AND DEMENTIA ACTION ALLIANCE.

IN 1985 WE WERE NOT AWARE OF THE FULL EXTENT OF ACTION NEEDED ON DEMENTIA. IN 2000 I COULD NOT HAVE DREAMED WE WOULD BE POSITIONED AS WE ARE TODAY TO TAKE FORWARD OUR ADVOCACY ON DEMENTIA AT THE INTERNATIONAL AND NATIONAL LEVELS.

WORKING TOGETHER WE HAVE EARNED THE RIGHT TO DREAM OF A BETTER FUTURE FOR PEOPLE WITH DEMENTIA AND THEIR FAMILY CARERS AND SUPPORTERS.

I BELIEVE WE KNOW WHAT TO DO TO ACHIEVE THOSE DREAMS. PEOPLE WITH DEMENTIA NEED TO KNOW THAT GLOBALLY NATIONS ARE JOINING TOGETHER TO HELP FIND THAT BETTER FUTURE WHERE THEY HAVE A VOICE AND THE RIGHT TO HOPE THROUGH ACCESS TO SUPPORT AND DEMENTIA SERVICES AND INCREASED GLOBAL SPENDING ON RESEARCH.