

GLOBAL PROGRESS: LOCAL IMPACT

ALZHEIMER'S SCOTLAND: DEMENTIA AWARENESS WEEK 2015

INTERNATIONAL DEVELOPMENTS

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CHAIR ALZHEIMER'S DISEASE INTERNATIONAL

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MY SINCERE THANKS TO ALZHEIMER'S SCOTLAND FOR THE INVITATION TO SPEAK TO YOU DAY. IT IS MY FIRST ENGAGEMENT AS CHAIR OF ALZHEIMER'S DISEASE INTERNATIONAL (ADI).

MY VISIT HAS GIVEN ME AN OPPORTUNITY THANKS TO THE WONDERFUL ORGANISATION OF KIRSTY WILSON TO LEARN FIRST HAND ABOUT THE WORK ALZHEIMER'S SCOTLAND DOES HAVING MUCH ADMIRING YOUR COMMITMENT TO CONSUMER ENGAGEMENT AND POLICY DEVELOPMENT OVER MANY YEARS.

MY ROLE IS TO SET THE SCENE AT THE GLOBAL LEVEL.

WE CAN I THINK BE WELL PLEASED WITH THE INCREASED GLOBAL RECOGNITION OF DEMENTIA AS A HEALTH PRIORITY. BUT WE MUST BE 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. HOW MUCH MORE DIFFICULT WORLD WIDE NOW IN TIMES OF FISCAL AUSTERITY AND FOR LOW AND MIDDLE INCOME COUNTRIES WITH WEAK HEALTH SYSTEMS.

I REMAIN OF THE VIEW I HAVE HELD FOR MANY YEARS 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. AND LET ME ADD THAT THE DRIVING FORCE WILL HAVE TO COME FROM CIVIL SOCIETY AND IN PARTICULAR FROM ALZHEIMER'S ORGANISATIONS

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 INCLUDING THAT

- THE NUMBERS OF PEOPLE WITH DEMENTIA TODAY WILL GROW FROM 44 MILLION in 2013 TO 135 MILLION BY MID CENTURY
- THE COSTS OF DEMENTIA WORLDWIDE IN 2010 WERE \$604 BILLION US.
- 60 PER CENT OF THE DISEASE BURDEN FALLS ON LOW AND MIDDLE INCOME COUNTRIES.

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.

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
- UNITED NATIONS EFFORTS TO ESTABLISH RIGHTS OF ELDERLY PEOPLE

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

THIRD, THE INCREASING RECOGNITION OF DEMENTIA AS A PUBLIC HEALTH ISSUE AND WITH THAT THE POTENTIAL OF PREVENTION. THE FUN PART OF BEING AN ADVOCATE IS MYTH BUSTING – AND IN DEMENTIA WE HAVE PLENTY OF SCOPE!

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 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.

HOW DO WE FOCUS THE GLOBAL AGENDA?

WHO WILL BE THE DRIVERS OF TRANSFORMATION?

THE GLOBAL AGENDA

MY SUGGESTION IS THAT WE SHOULD FOCUS THE GLOBAL AGENDA ON THREE PRIORITIES NAMELY TO

- TACKLE STIGMA THROUGH SOCIAL ACTION
- ESTABLISH DEMENTIA AS A PRIORITY THROUGH NATIONAL PLANS
- GIVE PRIORITY TO SUPPORTING ALZHEIMER'S ASSOCIATIONS IN LOW AND MIDDLE INCOME COUNTRIES

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

- THE SELF ADVOCACY OF PEOPLE WITH DEMENTIA AND THE PARTNERSHIP BETWEEN ADI AND THE DEMENTIA ALLIANCE INTERNATIONAL
- CREATING DEMENTIA FRIENDLY SOCIETIES

- BUILDING WORLDWIDE ON THE APPROACH OF JAPAN AND THE UK IN PROMOTING DEMENTIA FRIENDS
- 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, HIV-AIDS AND CARDIO-VASCULAR DISEASE.

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

ADI AND ALZHEIMER'S ORGANISATIONS MUST CONTINUE TO SUPPORT THE DEVELOPMENT OF PLANS BY UPDATING INFORMATION ON WHAT IS

HAPPENING AROUND THE WORLD, PROVIDING TECHNICAL SUPPORT AND RUNNING THE ALZHEIMER UNIVERSITY

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 IT IS IMPORTANT FOR ADI TO CONTINUE TO PROVIDE INFORMATION ABOUT THE EVIDENCE BASE FOR DEMENTIA AND RISK REDUCTION. THIS MAKES THE POINT NOT ONLY THAT SOME PEOPLE MAY BE ABLE TO DO SOMETHING THEMSELVES BUT THAT DEMENTIA LIKE OTHER CHRONIC DISEASES MUST BE TACKLED NOT ONLY THROUGH MEDICAL INTERVENTION BUT PREVENTION.

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 IN MARCH 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.

THE DRIVERS OF CHANGE

MY SECOND QUESTION WAS WHO WILL BE THE DRIVERS OF
TRANSFORMATION?

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?

UNCERTAINTY REMAINS BUT ONE OF THE POSSIBILITIES MIGHT BE TO
IDENTIFY COUNTRIES EACH PREPARED TO TAKE THE LEAD IN KEY AREAS

SUCH AS MODELS OF DEMENTIA CARE, THE QUALITY OF DEMENTIA CARE, PREVENTION, RESEARCH, OPEN SCIENCE AND IMPROVING RESEARCH COLLABORATION BETWEEN INDUSTRY, ACADEMIA AND GOVERNMENTS. WITHOUT LOCKING IN GOVERNMENT COMMITMENT IN SOMEWAY IT IS HARD TO SEE HOW THE MOMENTUM OF THE GLOBAL CHALLENGE CAN BE MAINTAINED.

SECOND, AMONG THE INTERNATIONAL ACTORS THE WHO 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 IS WORKING WITH GOVERNMENTS FOR A RESOLUTION IN 2016 AT THE WORLD HEALTH ASSEMBLY TO LAY THE BASIS FOR A PROGRAM OF 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 NEW 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 THE FORUM PROVIDED BY THE WORLD DEMENTIA COUNCIL

MAY PLAY A PART IN FOSTERING DISCUSSION BETWEEN GOVERNMENT, INDUSTRY, RESEARCHERS AND CONSUMERS.

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.

FOR MY PART I HOPE I CAN LOOK TO ALZHEIMER'S SCOTLAND TO WORK WITH ADI ON STRATEGIES TO EMPOWER CONSUMERS AND IN DEVELOPING POLICY AT THE GLOBAL LEVEL.

CONCLUSION

IT IS BY WORKING TOGETHER WE WILL EARN THE RIGHT TO DELIVER A BETTER FUTURE FOR PEOPLE WITH DEMENTIA AND THEIR FAMILIES

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