

**DEMENTIA RESEARCH: ADVOCACY, POLICY AND CARE  
RESEARCH AUSTRALIA  
2013 PHILANTHROPY FOR HEALTH AND MEDICAL RESEARCH CONFERENCE**

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**I AM PLEASED TO HAVE BEEN ASKED TO TALK AT THIS IMPORTANT CONFERENCE THIS EVENING ABOUT RESEARCH, ADVOCACY, POLICY AND CARE.**

**I'VE SPENT ALMOST 30 YEARS OF MY LIFE AS AN ADVOCATE TO ACHIEVE BETTER HEALTH OUTCOMES FOR PEOPLE WITH CHRONIC DISEASES – THESE INTERESTS HAVE SPANNED HIV/AIDS, MACULAR DEGENERATION, ARTHRITIS AND MORE RECENTLY, DEMENTIA.**

**DURING THAT TIME I HAVE HAD THE OPPORTUNITY TO REFLECT ON THE METAMORPHOSIS OF NON GOVERNMENT ORGANISATION, THEIR ROLE AS AGENTS OF CHANGE, AND THE IMPORTANCE OF RESEARCH TO THE WORK WE ALL DO.**

**LET ME START BY TELLING YOU ABOUT ALZHEIMER'S AUSTRALIA.**

**AS THE PEAK NATIONAL BODY, ALZHEIMER'S AUSTRALIA ADVOCATES ON BEHALF OF THE ESTIMATED 321,000 PEOPLE WITH DEMENTIA IN AUSTRALIA AND THE 1.2 MILLION PEOPLE WHO SUPPORT THEM.**

**OUR FUNCTION IS TO ACHIEVE BETTER OUTCOMES FOR THESE PEOPLE FROM AUSTRALIA'S HEALTH AND AGED CARE SYSTEMS. BETTER OUTCOMES OFTEN REQUIRE MORE MONEY, AND MAKING THE CASE FOR INVESTMENT IN SERVICES IS A MAJOR PART OF OUR ROLE.**

HOWEVER, WE ARE ALSO HEAVILY COMMITTED TO THE PROMISE OF BETTER OUTCOMES FOR THE FUTURE THROUGH RESEARCH, AND WE WORK CLOSELY WITH BOTH GOVERNMENTS AND PHILANTHROPISTS IN PURSUIT OF THIS GOAL – IN FACT WE ARE ALWAYS LOOKING FOR NEW PHILANTHROPISTS TO HELP US ACHIEVE OUR GOALS.

MOST IMPORTANTLY, WE ARE LIVING IN A TIME OF GREAT OPPORTUNITY FOR HEALTH AND AGED CARE REFORM, THE NATIONAL DISABILITY INSURANCE SCHEME, AND OF COURSE, THE MCKEON REVIEW.

THESE OPPORTUNITIES WILL TRANSCEND THE COMING ELECTION, AND FOR THAT REASON THERE IS AN AIR OF EXCITEMENT IN BEING PART OF AN NGO WHICH HAS A CLEAR VISION AND COMMITMENT TO ACHIEVING CHANGE FOR ITS STAKEHOLDERS.

IT'S THE KIND OF ENTHUSIASM THAT IS NEEDED TO BREAK DOWN BARRIERS AND I THINK THAT IS WHAT IS STARTING TO HAPPEN IN THE AREA OF DEMENTIA.

RESEARCH ADVOCACY IS A KEY PART OF OUR ROLE.

ALZHEIMER'S AUSTRALIA HAS A STANDING REQUEST TO THE FEDERAL GOVERNMENT TO INVEST AN ADDITIONAL \$200 MILLION IN DEMENTIA RESEARCH OVER THE NEXT FIVE YEARS.

**THIS WOULD MORE THAN DOUBLE NH&MRC FUNDING FOR DEMENTIA RESEARCH TO APPROXIMATELY \$70 MILLION PER ANNUM; OR 1.4 PER CENT OF THE \$4.9 BILLION AUSTRALIA SPENDS EACH YEAR ON DEMENTIA IN HEALTH AND AGED CARE.**

**IT WOULD ALSO BRING DEMENTIA RESEARCH FUNDING TO A LEVEL COMMENSURATE WITH FUNDING FOR OTHER CHRONIC CONDITIONS SUCH AS CANCER, DIABETES AND CARDIOVASCULAR DISEASE IN RELATION TO ECONOMIC COSTS AND DISEASE BURDEN.**

**WE UNDERSTAND THAT THE NH&MRC ALLOCATES MOST OF ITS FUNDING ON A COMPETITIVE BASIS AND THAT DEMENTIA RESEARCHERS HOLD THEIR OWN IN TERMS OF THEIR SUCCESS WITH COMPETITIVE FUNDING APPLICATIONS.**

**HOWEVER, IN THE SAME WAY AS OLYMPIC MEDALS ARE DOMINATED BY SPORTING GIANTS LIKE CHINA AND THE USA, OUR COMPETITIVE RESEARCH FUNDING FAVOURS WELL-ESTABLISHED RESEARCH AREAS WITH THE CAPACITY AND THE NETWORKS TO DOMINATE COMPETITION FOR LIMITED FUNDING.**

**I'M NOT SAYING THAT ANY OF THIS RESEARCH IS UNIMPORTANT, AND I'M CERTAINLY NOT IMPLYING THAT FUNDING FOR CANCER OR CARDIOVASCULAR DISEASE RESEARCH SHOULD BE REDUCED.**

**HOWEVER, THE SYSTEM FAILS TO RESPOND IN A TIMELY WAY TO EVOLVING HEALTHCARE CHALLENGES SUCH AS DIABETES AND DEMENTIA WITH THE RESEARCH EFFORT THAT IS NEEDED TO ADDRESS THEM.**

**UNFORTUNATELY ALZHEIMER'S AUSTRALIA WASN'T SUCCESSFUL IN ACHIEVING A COMMITMENT TO DEMENTIA RESEARCH IN THIS YEAR'S FEDERAL BUDGET, BUT WE ARE CAMPAIGNING HARD ON THE ISSUE IN THE LEAD-UP TO THE ELECTION.**

**WE WERE ENCOURAGED HOWEVER TO SEE A COMMITMENT TO DEMENTIA RESEARCH FROM STATE GOVERNMENTS INCLUDING \$9 MILLION ANNOUNCED BY QUEENSLAND IN MAY AND \$2.4 MILLION ANNOUNCED BY WESTERN AUSTRALIA LAST WEEK TO SUPPORT THE WORK OF PROFESSOR RALPH MARTINS AND THE MCCUSKER ALZHEIMER'S FOUNDATION.**

**I WAS ALSO PLEASED TO HEAR THE ANNOUNCEMENT THIS MORNING OF LABOR'S INITIAL RESPONSE TO THE MCKEON REVIEW. THIS INCLUDES PLANS FOR A \$250 MILLION MEDICAL RESEARCH INNOVATION FUND, MORE FUNDING FOR RESEARCH PRIORITY AREAS, AND MEASURES TO IMPROVE GRANT APPLICATION PROCESSES AND RESEARCH LEADERSHIP WITHIN THE NH&MRC.**

**THE NEW INVESTMENT FUND WILL GO TOWARDS BIOTECHNOLOGY INNOVATION IN AREAS SUCH AS REGENERATIVE MEDICINE, THE GROWING FOCUS IN NEUROSCIENCE AND DEMENTIA RESEARCH, AND ONE OF THE MOST EXCITING.**

**AND LET ME PAY TRIBUTE TO THE LEADERSHIP OF SIMON MCKEON FOR THE WORK HE AND HIS COMMITTEE DID ON PRODUCING THE REVIEW...AND REMIND YOU THAT SIMON WAS THE 2011 AUSTRALIAN OF THE YEAR. WE AUSTRALIANS OF THE YEAR HAVE OUR USES!**

**ALZHEIMER'S AUSTRALIA WORKS CLOSELY WITH GOVERNMENT AND OTHER PARTNERS TO ACHIEVE THE POLICY CHANGES REQUIRED FOR BETTER DEMENTIA CARE.**

**A GOOD EXAMPLE IS OUR WORK ON CONSUMER DIRECTED CARE (CDC) THAT GIVES PEOPLE CHOICE OF THE SERVICES THAT BEST RESPOND TO THEIR NEEDS AND CONTROL OVER HOW, WHERE AND WHEN THEY ARE DELIVERED.**

**OUR WORK IN THIS AREA BEGAN 12 YEARS AGO WHEN WE COMMISSIONED A REPORT FROM AUSTRALIAN RESEARCHERS TO DRAW TOGETHER THE EVIDENCE BASE ON CONSUMER DIRECTED CARE.**

WE FOLLOWED THIS UP WITH A SECOND REPORT ON INTERNATIONAL EXPERIENCE AND A SERIES OF NATIONAL WORKSHOPS BEFORE TAKING THE EVIDENCE TO MINISTERIAL AND DEPARTMENTAL ADVISORY COMMITTEES WITH A CASE FOR IMPLEMENTATION.

TO CUT A TEN YEAR STORY SHORT, THE PRINCIPLE OF CDC WAS ONE OF THE MAJOR COMPONENTS OF THE \$3.7 BILLION *LIVING LONGER. LIVING BETTER.* AGED CARE REFORM PACKAGE ANNOUNCED BY THE GOVERNMENT LAST YEAR.

HOWEVER, DESPITE THE NEW POLICY, EMPOWERMENT AND CHOICE WILL NOT HAPPEN WITHOUT BUILDING THE CAPACITY OF BOTH THE CONSUMER AND THE PROVIDER. WITHOUT SUPPORT CONSUMERS WILL NOT KNOW WHAT OPTIONS TO CONSIDER AND PROVIDERS WILL NOT KNOW HOW TO MANAGE THE BALANCE OF RISK AND CHOICE.

I AM NOT SURE THAT WE KNOW YET HOW TO ACHIEVE THE OBJECTIVES OF CDC.

IN THIS AREA OUR WORK AND THAT OF OTHER CONSUMER ORGANISATIONS NEEDS TO BE STRENGTHENED BY EVIDENCE- BASED RESEARCH.

**IT WOULD BE NAIVE TO BELIEVE THAT MANY CONSUMERS ARE NOT SCEPTICAL ABOUT WHAT CDC MEANS IF ACCESS TO BASIC SERVICES CANNOT BE ACHIEVED IN THE CURRENT SYSTEM IN RECEIVING GOOD INFORMATION, PROMPT ASSESSMENT AND PROMPT REFERRAL SERVICES.**

**THE QUESTION IS HOW DECISION MAKING CAN BE MADE TO WORK NOT ONLY IN THE MAINSTREAM BUT FOR THOSE WHO ARE DISADVANTAGED IN OUR SOCIETY.**

**FOR EXAMPLE, WE KNOW SO LITTLE ABOUT HOW PEOPLE WITH DEMENTIA PERCEIVE THE WORLD. HOW CAN WE ENSURE THAT DECISION MAKING RESPONDS TO THEIR OFT QUOTED DEMAND “NOTHING ABOUT US WITHOUT US”.**

**AND HOW DO WE RESPOND TO THE PLAINTIVE CALL...“I AM STILL HERE”.**

**THERE IS SO LITTLE RESEARCH ON HOW DECISIONS ARE TAKEN IN DECIDING THE SUPPORT AND SERVICES THAT OLDER PEOPLE NEED. WE KNOW EVEN LESS ABOUT WHAT IS INVOLVED IN ENSURING PEOPLE WITH DEMENTIA CAN BE ENCOURAGED TO RETAIN A PURPOSE IN LIFE BY HAVING A POWER OF DECISION AND SELF DETERMINATION.**

**UNTIL RECENT TIMES, SOCIETAL ATTITUDES FOR THE MOST PART, HAVE DENIED PEOPLE WITH DEMENTIA THE POSSIBILITY OF BEING INVOLVED IN DECISION MAKING.**



**WE NEED MORE RESEARCH TO HELP US UNDERSTAND HOW TO MAKE SURE PEOPLE WITH DEMENTIA AND THEIR FAMILY CARERS ARE ABLE TO PARTICIPATE AS FULLY AS THEY WOULD LIKE IN DECISION MAKING WHILE RECOGNISING THEIR ABILITY TO DO SO IS COMPROMISED BY THE NATURE OF DEMENTIA.**

**HOW CAN WE HELP THEM TO MAINTAIN A SENSE OF CONTROL OVER THEIR OWN LIVES WHILE WANTING THEM TO ACCEPT SOME SUPPORT AND ASSISTANCE?**

**OR AGAIN, HOW CAN PEOPLE WITH DEMENTIA HOLD ON TO THEIR DECISION MAKING CAPABILITIES FOR AS LONG AS POSSIBLE IN ISSUES SUCH AS DRIVING OR CONTINUING TO WORK...OR LET ME PUT IT THIS WAY... HOW TO BALANCE HANGING ON, VERSUS LETTING GO.**

**HOW CAN WE MAKE PEOPLE WITH DEMENTIA FEEL THEY ARE CENTRAL TO THE DECISION MAKING THAT IMPACTS ON THEIR LIVES?**

**THE COMMON THEME AMONG DISADVANTAGED GROUPS IS LACK OF TRUST – WHETHER THE HOMELESS, THE NEWER IMMIGRANT GROUPS OR LGBTI. I BELIEVE WE NEED TO UNDERSTAND MORE ABOUT HOW WE CAN BEST GAIN THEIR TRUST AND NEGOTIATE IN PARTNERSHIP THE SERVICES THEY NEED.**

**FOR GROUPS SUCH AS THE HOMELESS, WHERE TRUST IN THE SOCIETY AROUND THEM HAS BEEN ERODED, THERE MAY BE VERY LITTLE RECOGNITION OF THE BAD DECISIONS THEY ARE TAKING AND HOW THESE DECISIONS AFFECT THEIR LIVES. AT THE SAME TIME, THEY ARE UNLIKELY TO HAVE PEOPLE TO SUPPORT THEM.**

**MANY FROM THE LGBTI GROUPS WILL HAVE EXPERIENCED DISCRIMINATION IN THEIR LIVES AND WOULD LIKE TO RETAIN THEIR PRIVACY RATHER THAN HAVE AN INVASION BY COMMUNITY SERVICES HOWEVER WELL INTENTIONED.**

**THEY ARE MORE LIKELY TO LIVE ALONE OR HAVE CHILDREN TO SUPPORT THEM.**

**AND HOWEVER WELL MEANING POLICY MAKERS ARE IN DESIGNING PERSON CENTRED CARE AND CDC, PEOPLE IN THE NEWER IMMIGRANT COMMUNITIES ARE LIKELY TO FALL THROUGH THE GAPS AND BECOME MARGINALISED.**

**I AM STRUCK BY THE FACT THAT THESE ISSUES DO NOT OFTEN ENTER OUR DISCOURSE EXCEPT IN THE FORM OF HIGH LEVEL STRATEGIES, UNINFORMED FOR THE MOST PART, BY EVIDENCE OF THE ISSUES AND STRATEGIES NECESSARY TO RESPOND.**

**I NOW WANT TO TALK ABOUT KNOWLEDGE TRANSLATION. IT IS THE APPLICATION OF RESEARCH IN PRACTICE THAT ALZHEIMER'S AUSTRALIA HAS ALWAYS RECOGNISED AS IMPORTANT AND IT HAS BEEN A FEATURE OF THE WORK WE HAVE DONE IN KNOWLEDGE TRANSLATION IN PARTNERSHIP WITH MANY OTHERS**

**IN 2010 WE ESTABLISHED THE NATIONAL QUALITY DEMENTIA CARE INITIATIVE WITH \$3.3 MILLION FUNDING FROM THE JO & JR WICKING TRUST, BUPA CARE SERVICES AND THE DEMENTIA COLLABORATIVE RESEARCH CENTRES WITH THE OBJECTIVE OF FAST-TRACKING THE TRANSLATION OF EXISTING RESEARCH EVIDENCE INTO IMPROVED DEMENTIA CARE.**

**WHAT MAKES THIS PROGRAM STAND OUT FROM OTHERS IS ITS EMPOWERMENT OF PEOPLE LIVING WITH DEMENTIA TO SET PRIORITIES AND MAKE FUNDING DECISIONS, ITS EXTENSIVE PARTNERSHIP WITH RESEARCHERS AND SERVICE PROVIDERS, AND ITS INSISTENCE ON SUSTAINABLE, NATIONAL ACTIVITIES.**

**WE HAVE FUNDED EIGHT PROJECTS THROUGH THIS INITIATIVE AND SOME FANTASTIC NATIONAL WORK IS BEING DONE TO IMPROVE DEMENTIA DIAGNOSIS, PALLIATIVE CARE, ADVANCE CARE PLANNING AND DEMENTIA ENABLING DESIGN.**

**THESE PROJECTS ARE ALL BASED ON PARTNERSHIP, AND INVOLVE A RANGE OF UNIVERSITIES, SERVICE PROVIDERS AND OTHER NOT FOR PROFITS, INCLUDING THE HEART FOUNDATION.**

**ONE PROJECT THAT I LAUNCHED IN MELBOURNE LAST MONTH IN MELBOURNE PROMOTES AN EXCITING NEW APPROACH TO DEMENTIA CARE BASED ON MONTESSORI EDUCATION PRINCIPLES.**

**THE NOVEL CONCEPT HERE IS THAT PEOPLE WITH DEMENTIA ARE STILL PEOPLE – SOMETHING I CONSTANTLY REMIND PEOPLE....HOWEVER THEY ARE PEOPLE WITH A MEMORY DISABILITY. IT IS BASED ON GOOD EVIDENCE THAT EVEN WITH A MEMORY DISABILITY, PEOPLE CAN STILL LEARN, AND THAT THERE ARE SYSTEMATIC AND SOMETIMES NON-VERBAL APPROACHES TO LEARNING THAT CAN HELP PEOPLE TO COPE WITH THEIR MEMORY DISABILITY AND THUS ENHANCE THEIR INDEPENDENCE AND QUALITY OF LIFE.**

**ANOTHER PROJECT IS HELPING CONSUMERS AND DESIGNERS TO MODIFY BUILT AND OUTDOOR ENVIRONMENTS IN A WAY THAT HELPS RATHER THAN HINDERS PEOPLE WITH DEMENTIA.**

**IF WE BUILD NURSING HOMES WITH IDENTICAL CORRIDORS AND IDENTICAL DOORS, IS IT ANY WONDER THAT PEOPLE WITH A MEMORY DISABILITY MIGHT 'WANDER' INTO OTHER PEOPLE'S ROOMS?**

**THE GREAT THING ABOUT THIS PROJECT IS THAT WE HAVE MADE PROGRESS IN HAVING THE CONCEPT OF COGNITIVE ACCESSIBILITY INCORPORATED INTO BUILDING CODES AND DESIGN STANDARDS, MUCH AS HAS BEEN ACHIEVED WITH DISABILITY IN THE PAST 25 YEARS.**

**OUR NATIONAL OFFICE MANAGES THE NATIONAL QUALITY DEMENTIA CARE INITIATIVE, UNDER THE DIRECTION OF MEMBERS OF THE ALZHEIMER'S AUSTRALIA CONSUMER DEMENTIA RESEARCH NETWORK.**

**OUR WORK ON KNOWLEDGE TRANSLATION ALSO EXTENDS TO DEMENTIA RISK REDUCTION.**

**THERE IS NOW TWO DECADES OF RESEARCH SHOWING THAT THERE ARE THINGS EVERYONE CAN DO TO REDUCE THEIR RISK OF DEVELOPING DEMENTIA SUCH AS NOT SMOKING, DRINKING IN MODERATION, STAYING FIT AND HEALTHY, EATING WELL AND REMAINING MENTALLY AND SOCIALLY ENGAGED.**

**I MUST CONFESS TO TAKING GREAT SATISFACTION IN A NEW REPORT RELEASED IN FRANCE ONLY LAST MONTH THAT FOUND DELAYING RETIREMENT WAS ASSOCIATED WITH A LOWER RISK OF DEMENTIA.**

**I HADN'T PLANNED ON STOPPING ANY TIME SOON – RETIREMENT IS NOT A WORD IN MY VOCABULARY – BUT NOW I HAVE VERY POSITIVE EVIDENCE TO GIVE TO ANYONE WHO SUGGESTS I SHOULD THINK ABOUT SLOWING DOWN.**

**WITH FUNDING FROM THE COMMONWEALTH ALZHEIMER'S AUSTRALIA IS DELIVERING THE WORLD'S FIRST PUBLICLY FUNDED NATIONAL DEMENTIA RISK REDUCTION PROGRAM, YOUR BRAIN MATTERS. THIS PROGRAM TAKES A CAMPAIGN APPROACH USING TRADITIONAL AND SOCIAL MEDIA AND INTERACTIVE ELEMENTS INCLUDING AN IPHONE APP WITH OVER 300,000 USERS TO ENCOURAGE PEOPLE TO LOOK AFTER THEIR HEART AND LOOK AFTER THEIR BRAIN.**

**MY COLLEAGUES AT ALZHEIMER'S AUSTRALIA AND I ARE PASSIONATE ABOUT BUILDING CAPACITY IN DEMENTIA RESEARCH**

**HOWEVER IN BUILDING A SUSTAINABLE RESEARCH BASE, IT SEEMS AGAIN WE CANNOT RELY ON THE NH&MRC. THERE WERE JUST 56 GRANTS, SCHOLARSHIPS AND FELLOWSHIPS AWARDED TO NEW AND EARLY CAREER DEMENTIA RESEARCHERS THROUGH THE NH&MRC BETWEEN 2002 AND 2011, COMPARED TO OVER 700 IN CANCER, 500 FOR CARDIOVASCULAR DISEASE, 271 IN MENTAL HEALTH AND 250 IN DIABETES..**

**UNLESS WE CAN SUPPORT THE BEST AND BRIGHTEST RESEARCHERS AND ENCOURAGE THEM INTO DEMENTIA RESEARCH, WE WILL ALL HAVE TO LIVE WITH THE CONSEQUENCES OF DELAYED PROGRESS IN OUR UNDERSTANDING OF THE DISEASE.**

**OUR EFFORTS TO ADDRESS THIS ARE BASED ON A PARTNERSHIP WITH PHILANTHROPISTS AND MEMBERS OF THE PUBLIC, WHO SUPPORT NEW DEMENTIA RESEARCHERS THROUGH THE ALZHEIMER'S AUSTRALIA DEMENTIA RESEARCH FOUNDATION.**

**THE FOUNDATION HAS SUPPORTED 108 EARLY CAREER DEMENTIA RESEARCHERS WITH \$3.65 MILLION FUNDING BETWEEN 2000 AND 2011; AND WILL PROVIDE OVER \$2.5 MILLION IN GRANTS, SCHOLARSHIPS AND FELLOWSHIPS THIS YEAR. OF THESE 108 NEW INVESTIGATORS, OVER 70% ARE STILL WORKING IN THE FIELD, AND BETWEEN THEM THEY HAVE SECURED A FURTHER \$65 MILLION IN RESEARCH FUNDING AND PUBLISHED OVER 1250 ACADEMIC PAPERS.**

**I THINK THAT IS AN EXCELLENT OUTCOME.**

**THERE'S NO DOUBT IN MY MIND THAT AN NGO CAN BE AN AGENT OF CHANGE. IN THE CASE OF ALZHEIMER'S AUSTRALIA THE PRIMARY OBJECTIVE HAS BEEN TO ACHIEVE CHANGE IN THE HEALTH AND CARE SYSTEM TO IMPROVE THE QUALITY OF LIFE OF PEOPLE WITH DEMENTIA.**

**NONE OF WHAT I HAVE TALKED ABOUT TONIGHT WOULD HAVE BEEN POSSIBLE WITHOUT RESEARCH AND AN EVIDENCE BASE ON WHICH TO SUPPORT OUR ADVOCACY AND KNOWLEDGE TRANSLATION ACTIVITIES.**

**MOST IMPORTANT OF ALL HAVE BEEN OUR COMMITMENT TO PARTNERSHIP WITH OTHERS WHICH IS EXACTLY THE WAY WE INTEND TO CONTINUE WORKING IN THE FUTURE.**

**THANK YOU.**