

**NATIONAL HEALTH AND MEDICAL RESEARCH COUNCIL
RESEARCH TRANSLATION SYMPOSIUM – FROM BENCH TO BOURKE**

DOLTONE HOUSE, PYRMONT

OCTOBER 2, 2013

**ITA BUTTROSE AO, OBE
PRESIDENT, ALZHEIMER'S AUSTRALIA**

I APPRECIATE THE OPPORTUNITY TO SPEAK AT THIS DINNER TONIGHT.

AS AUSTRALIAN OF THE YEAR, I FEEL FORTUNATE TO BE ABLE TO USE MY POSITION TO KEEP HEALTH ISSUES, PARTICULARLY THOSE RELATED TO MEDICAL RESEARCH AND POSITIVE AGEING, HIGH ON THE PUBLIC AND POLITICAL AGENDA.

I'M VERY POSITIVE ABOUT AGEING...AGEING WELL THAT IS...BECAUSE IT'S A WORLD TO WHICH WE ARE ALL HEADED, IF WE ARE LUCKY. AS I LIKE TO SAY ...NOT EVERY ONE GETS TO BE OLD; YOU HAVE TO BE LUCKY TO GET TO BE OLD

SO I ALWAYS FEEL LIKE CHEERING WHEN THERE'S A NEW FINDING IN MEDICAL SCIENCE WHICH PROVIDES GREATER INSIGHT INTO THE CAUSES, CURE AND CARE OF CHRONIC DISEASES THAT CAUSE SO MUCH SUFFERING FOR SO MANY AUSTRALIANS...AND THESE FINDINGS SEEM TO BE HAPPENING ALMOST EVERY DAY.

WHAT CAN BE MORE IMPORTANT THAN MEDICAL DISCOVERY? THE CHALLENGE OF ADVANCING OUR UNDERSTANDING OF HUMAN HEALTH AND DISEASE OFFERS THE PROMISE OF HELPING US ALL TO ENJOY LONGER, HEALTHIER LIVES.

WITH IT COMES THE HOPE THAT THE DEDICATION AND INTELLECTUAL FEATS OF MEDICAL RESEARCHERS MIGHT SOON LEAD TO NEW WAYS OF TREATING DEVASTATING CONDITIONS SUCH AS MACULAR DEGENERATION, OR TO FURTHER EXTEND THE LIVES OF PEOPLE WITH CANCER OR HIV/AIDS.

HEALTH AND MEDICAL RESEARCH ALSO PROVIDE NEW INSIGHTS IN HOW TO PROVIDE BETTER CARE AND SUPPORT TO PEOPLE WHO HAVE DEMENTIA.

PERHAPS WHAT EXCITES ME MOST HOWEVER IS THE HOPE THAT DURING OUR OWN CHILDREN'S LIFETIMES, RESEARCH MAY ENABLE US TO PREVENT OR EVEN ELIMINATE ALTOGETHER THE DISEASES THAT LEAD TO DEMENTIA.

I'M SURE THE GOAL OF HELPING PEOPLE LIVE HEALTHIER LONGER LIVES WHILE ENJOYING GREATER QUALITY OF LIFE IS WHAT DRIVES PEOPLE LIKE YOU WHO WORK IN THE HEALTH SECTOR – WHETHER IN RESEARCH, SERVICE PROVISION OR CONSUMER ADVOCACY.

FOR ANYONE LIVING WITH CONDITIONS SUCH AS ARTHRITIS, CANCER, DIABETES OR DEMENTIA, RESEARCH OFFERS THE SOMETIMES DESPERATE EXPECTATION THAT NEW TREATMENTS TO REVERSE, DELAY OR ALLEVIATE SYMPTOMS MIGHT BE DEVELOPED OR, AT THE VERY LEAST, A SENSE OF OPTIMISM THAT TREATMENTS MAY BE AVAILABLE FOR THE NEXT GENERATION.

I'M SURE MANY OF YOU ARE AWARE OF RESEARCH AUSTRALIA'S ANNUAL SURVEY THAT CONSISTENTLY HAS FOUND MEMBERS OF THE PUBLIC RATE HEALTH AND MEDICAL RESEARCH AS ONE OF THE TOP PRIORITIES FOR AUSTRALIA. I DON'T FIND THAT VERY SURPRISING DO YOU?

INVESTMENT IN HEALTH AND MEDICAL RESEARCH IS SO IMPORTANT TO AUSTRALIANS THAT AROUND 40 PER CENT REPORT MAKING AT LEAST ONE DONATION EACH YEAR TO HEALTH AND MEDICAL RESEARCH. NEARLY HALF THINK THEY SHOULD BE DONATING MORE THAN THEY ALREADY ARE...WHAT A GOOD IDEA!

SIMILAR SURVEYS HAVE FOUND THAT MEDICAL RESEARCHERS ARE AMONG THE MOST HIGHLY TRUSTED PROFESSIONALS IN OUR COMMUNITY.

SO THERE YOU HAVE IT. AUSTRALIANS TRUST MEDICAL RESEARCHERS, THEY THINK WHAT MEDICAL RESEARCHERS DO IS OF UTMOST IMPORTANCE, THEY ARE NOT ONLY EXCITED BY THE WORK MEDICAL RESEARCHERS DO BUT ALSO WANT TO HELP SUPPORT THAT WORK AND ARE DEPENDING ON RESEARCHERS, LIKE MANY OF YOU IN THIS ROOM TONIGHT, TO SUCCEED.

THERE ARE FEW IN OUR COMMUNITY WHO ARE HELD IN SUCH HIGH REGARD. IT'S ENCOURAGING TO HAVE SUCH SUPPORT. ALZHEIMER'S AUSTRALIA IS A STRONG SUPPORTER OF MEDICAL RESEARCH. I BELIEVE OUR ORGANISATION HAS AN EVEN BIGGER ROLE TO PLAY IN CONTRIBUTING TO A STRONGER DEMENTIA RESEARCH SECTOR.

AS AN EDITOR AND JOURNALIST, I KNOW THE KINDS OF HEADLINES THAT ATTRACT THE ATTENTION OF READERS AND VIEWERS. IN DEMENTIA, THESE ARE HEADLINES SUCH AS: 'SCIENTISTS DISCOVER NEW TREATMENTS FOR ALZHEIMER'S DISEASE'. UNFORTUNATELY, WISHFUL THINKING TO DATE.

HOWEVER, WE HAVE EMINENT RESEARCHERS HERE IN AUSTRALIA WHO ARE CONTRIBUTING TO THE INTERNATIONAL EFFORT BY LAYING THE BUILDING BLOCKS FOR PROGRESS.

FOR EXAMPLE, THE AUSTRALIAN IMAGING, BIOMARKERS AND LIFESTYLE FLAGSHIP STUDY OF AGEING, LED BY THE CSIRO AND INVOLVING LEADING RESEARCHERS FROM ACROSS AUSTRALIA HAS SHOWN THAT THE PRESENCE OF ALZHEIMER'S DISEASE CAN BE DETECTED IN THE BRAIN ALMOST 20 YEARS BEFORE SYMPTOMS FIRST APPEAR.

THIS LEADS TO THE SOBERING THOUGHT THAT SOME OF US HERE PROBABLY HAVE AN UNDIAGNOSED, PRE-SYMPTOMATIC NEURODEGENERATIVE DISEASE.

BUT AT THE SAME TIME, THIS FINDING ALSO PROVIDES A WHOLE NEW WORLD OF OPPORTUNITY FOR RESEARCH INTO TREATMENTS TO MODIFY THE DISEASE PROCESS.

LIKE OTHER CHRONIC DISEASES, DEMENTIA WILL BE ONLY TACKLED EFFECTIVELY IF TREATMENT CAN BEGIN BEFORE TOO MUCH DAMAGE OCCURS.

WE HAVE BEEN SLOW TO LEARN THAT DEMENTIA IS NOT JUST A DISEASE OF OLD AGE. RECENT STUDIES IN THE UK AND DENMARK REMIND US THAT CONVENTIONAL THINKING ABOUT THE IMMUTABILITY OF DEMENTIA PREVALENCE RATES MAY BE HORRIBLY WRONG.

THE FINDINGS OF THESE STUDIES CHALLENGE THE ASSUMPTION THAT PREVALENCE RATES OF DEMENTIA ARE CONSTANT ACROSS GENERATIONS; THAT THE NUMBERS OF PEOPLE WITH DEMENTIA IS SIMPLY A FUNCTION OF THE NUMBER OF OLDER PEOPLE IN THE POPULATION.

IN FACT, FOR A GIVEN POPULATION COHORT, THE RISK OF DEVELOPING ALZHEIMER'S MIGHT ACTUALLY GO DOWN.

OVER THE LAST TWO DECADES IN ENGLAND AND WALES, DEMENTIA RATES WERE SHOWN TO HAVE DROPPED BY 24 PER CENT AMONG THOSE 65 AND OLDER.

IN DENMARK THE PERCENTAGE OF THOSE AGED OVER 90 WHOSE COGNITIVE ABILITIES WERE SEVERELY IMPAIRED ALSO DROPPED BETWEEN 1998 AND 2010.

THE COMPLEXITY OF THE ARGUMENT IS THAT ALTHOUGH THE RISK OF DEMENTIA FOR ANY POPULATION MAY DECLINE OVER TIME – AND EVEN THAT MAY BE UNCERTAIN – THE TOTAL NUMBER OF PEOPLE WITH DEMENTIA WILL CONTINUE TO RISE AS LONG AS OUR POPULATION CONTINUES TO GET OLDER.

WHAT WE NOW KNOW IS THAT SUCCESSIVE GENERATIONS OR EVEN SLIGHTLY YOUNGER COHORTS SEPARATED BY AS LITTLE AS 10 YEARS MIGHT NOT HAVE THE SAME RISK.

IT IS A LOVELY THOUGHT THAT OUR GRANDCHILDREN MAY BE LESS LIKELY TO DEVELOP DEMENTIA THAN WE ARE.

THE STUDIES I'VE TALKED ABOUT ARE OBSERVATIONAL STUDIES AND NOT RANDOMISED CONTROLLED TRIALS SO THEY DON'T TELL US A LOT ABOUT THE CAUSES.

IN THEIR INTERPRETATION THE AUTHORS OF THE UK STUDY SAID: "THE SCALE OF REDUCTION THAT WE IDENTIFIED IS SUBSTANTIAL AND IN LINE WITH MAJOR REDUCTIONS IN RISK FACTORS IN HIGHER INCOME COUNTRIES, WHICH HAVE BEEN MODIFIED BY SOCIETAL CHANGES SUCH AS IMPROVEMENTS IN EDUCATION AND PREVENTION, AND TREATMENT STRATEGIES IN RECENT DECADES".

THEY GO ON TO MAKE AN OBSERVATION THAT IS OF GREAT INTEREST TO ALL OF US AT ALZHEIMER'S AUSTRALIA: "ALTHOUGH MAJOR FACTORS COULD HAVE INCREASED DEMENTIA, PREVALENCE AT SPECIFIC AGES – SUCH AS THOSE ASSOCIATED WITH DIABETES, SURVIVAL AFTER STROKES AND VASCULAR INCIDENTS – OTHER FACTORS THAT COULD DECREASE PREVALENCE SUCH AS IMPROVED PREVENTION OF VASCULAR MORBIDITY AND HIGHER LEVELS OF EDUCATION SEEM TO HAVE A GREATER EFFECT."

NATURALLY THERE IS THE INEVITABLE CAVEAT ABOUT THE NEED FOR FURTHER RESEARCH BUT THE UK AND DENMARK STUDIES DO OFFER AN ENCOURAGING GLIMMER OF HOPE. ALZHEIMER'S AUSTRALIA SEES INVESTMENT IN STUDIES INTO DEMENTIA PREVALENCE AS A VITAL PART OF THE GREATER INVESTMENT THAT IS NEEDED IN DEMENTIA RESEARCH.

WE DO NEED TO KNOW MORE ABOUT INCIDENCE AND THE NUMBERS OF PEOPLE WITH DEMENTIA TO PLAN SERVICES; CURRENTLY AUSTRALIA RELIES ON OVERSEAS DATA. WE BELIEVE THE TIME HAS COME TO RECTIFY THIS SITUATION.

WE HAVE PUT TOGETHER A PROPOSAL FOR AN AUSTRALIAN DEMENTIA PREVALENCE STUDY THAT WOULD LINK OTHER POPULATION STUDIES AND GIVE US DATA FOR THE FIRST TIME ON AUSTRALIAN DEMENTIA PREVALENCE. IT IS A COSTLY EXERCISE – \$10 MILLION AND WE WILL BE DISCUSSING THIS SHORTLY WITH THE NEW FEDERAL GOVERNMENT.

INVESTMENT IN STUDIES INTO DEMENTIA PREVALENCE AND PREVENTION NEEDS TO BE SEEN AS AN IMPORTANT PART OF THE GREATER INVESTMENT THAT IS NEEDED IN DEMENTIA RESEARCH.

WE SHOULD ALSO ASK HOW WE CAN PLAN HEALTH SERVICES WITHOUT AUSTRALIAN DATA THAT REFLECTS OUR LOCAL CIRCUMSTANCES.

OUR PRIMARY FOCUS FOR MANY YEARS HAS BEEN BIOMEDICAL RESEARCH AND WITH A TRACK RECORD OF INNOVATION AND DISCOVERY INCLUDING PENICILLIN, HELICOBACTER AND GARDASIL, THIS FOCUS HAS CLEARLY SERVED AUSTRALIA WELL.

HOWEVER, AS THE MCKEON REVIEW NOTED, THE RESEARCH ENVIRONMENT IS CHANGING.

NOT ONLY DO WE NEED TO ACHIEVE MUCH BETTER INTEGRATION OF HEALTH AND MEDICAL RESEARCH WITHIN THE HEALTH AND AGED CARE SYSTEMS, WE NEED TO BECOME MORE STRATEGIC ABOUT OUR USE OF LIMITED FUNDING GIVEN THE HIGH COSTS OF QUALITY RESEARCH AND SYSTEMATIC KNOWLEDGE TRANSLATION.

I AM IMPRESSED – OVERWHELMED MIGHT BE A BETTER WORD – BY THE RESOURCES IT TAKES TO MAKE ADVANCES. LAST MONTH, THE NATIONAL INSTITUTES OF HEALTH IN THE US AWARDED \$33.2 MILLION – THEIR LARGEST EVER DEMENTIA GRANT – FOR A STUDY TRIALLING DRUG TREATMENTS ON HEALTHY PEOPLE WITH A GENETIC PREDISPOSITION TO DEVELOPING ALZHEIMER’S DISEASE.

GOVERNMENTS IN THE UK AND EUROPE HAVE MADE SIGNIFICANT COMMITMENTS TO DEMENTIA RESEARCH IN RECENT YEARS AND AFTER TWO YEARS OF CAMPAIGNING, I’M PLEASED TO BE ABLE TO REPORT AUSTRALIA HAS FINALLY JOINED THIS ILLUSTRIOUS AND FORWARD THINKING GROUP OF COUNTRIES WHO ARE PROACTIVELY TACKLING DEMENTIA THROUGH A MAJOR INVESTMENT IN RESEARCH.

I CONGRATULATE PRIME MINISTER ABBOTT, AND THE MINISTER FOR HEALTH, PETER DUTTON, FOR TAKING THE INITIATIVE TO COMMIT AN ADDITIONAL \$200 MILLION OVER THE NEXT FIVE YEARS TO DEMENTIA RESEARCH.

ALZHEIMER'S AUSTRALIA IS LOOKING FORWARD TO WORKING WITH THE GOVERNMENT AND WITH THE NHMRC TO ENSURE THAT THIS MONEY IS WELL INVESTED.

I'M SURE WE'D ALL LIKE TO LEAVE A LEGACY THAT BUILDS ON THE GREAT ACHIEVEMENTS OF MEDICAL AND SCIENTIFIC RESEARCH IN AUSTRALIA.

ALZHEIMER'S AUSTRALIA BELIEVES THE ESTABLISHMENT OF A NEW NATIONAL DEMENTIA INSTITUTE WOULD CREATE OPPORTUNITIES FOR AN INNOVATIVE APPROACH TO TACKLING DEMENTIA AND BRINGING TOGETHER LEADING THINKERS FROM FIELDS SUCH AS IMMUNOLOGY, DIABETES AND CARDIOVASCULAR DISEASE.

ALL TOO OFTEN RESEARCH, INCLUDING THAT DONE IN THE FIELD OF DEMENTIA, IS CONSTRAINED WHEN THE OBJECTIVE SHOULD BE TO ENSURE DIFFERENT DISCIPLINES CAN CONTRIBUTE TO WHAT IS ONE OF THE MAJOR MEDICAL CHALLENGES OF THIS CENTURY.

A NEW NATIONAL DEMENTIA INSTITUTE WOULD PROVIDE THE OPPORTUNITY TO LIFT THE PROFILE OF DEMENTIA RESEARCH AND ENCOURAGE THE ENTRANCE OF NEW RESEARCHERS TO A FIELD THAT HAS BEEN SADLY NEGLECTED.

IT'S ESSENTIAL THAT THE NEW FUNDING IS USED TO DEVELOP DEMENTIA RESEARCH CAPACITY. WITHOUT NEW RESEARCHERS, WE WON'T HAVE THE CAPACITY TO ANSWER THE MANY PRESSING QUESTIONS THAT WE WILL FACE IN THE FUTURE.

A NATIONAL DEMENTIA INSTITUTE WOULD POSITION AUSTRALIAN RESEARCHERS TO COLLABORATE AND PARTNER MORE EFFECTIVELY WITH OVERSEAS RESEARCHERS WHOSE GOVERNMENTS HAVE SIMILARLY INVESTED IN DEMENTIA RESEARCH.

IN PARALLEL WITH A GREATER INVESTMENT IN DEMENTIA RESEARCH IS THE NEED TO GET THE EVIDENCE OF RESEARCH INTO PRACTICE TO PROVIDE BETTER HEALTH AND CARE OUTCOMES FOR AUSTRALIANS WHO ARE LIVING WITH DEMENTIA.

THE ALZHEIMER'S AUSTRALIA DEMENTIA RESEARCH FOUNDATION HAS BEEN WORKING HARD TO BUILD CAPACITY WITH SUPPORT FROM THE PUBLIC AND PHILANTHROPIC ORGANISATIONS.

I AM PROUD TO SAY THAT THE 108 NEW AND EARLY CAREER DEMENTIA RESEARCHERS, WHO HAVE RECEIVED \$4.4 MILLION FROM THE FOUNDATION OVER THE PAST DECADE, HAVE BETWEEN THEM PUBLISHED MORE THAN 1,100 PEER REVIEWED DEMENTIA PAPERS, AND SECURED ALMOST \$67 MILLION IN ADDITIONAL DEMENTIA RESEARCH FUNDING.

WE HOPE THAT THE EXCITEMENT OF HEALTH AND MEDICAL RESEARCH IN DEMENTIA AND OTHER AREAS ALONG WITH NEW GOVERNMENT FUNDING WILL ENABLE US TO WORK WITH THE NHMRC AND OTHERS TO BUILD DEMENTIA RESEARCH CAPACITY EVEN MORE.

BUT WE CAN'T DO THAT EFFECTIVELY CAN WE WITHOUT KNOWLEDGE TRANSLATION, THAT DECEPTIVELY SIMPLE-SOUNDING CONCEPT OF GETTING RESEARCH INTO PRACTICE.

IT SEEMS TO ME WE ARE ALL STRUGGLING TO DEFINE WHAT WE MEAN BY KNOWLEDGE TRANSLATION; OFTEN WE EACH MEAN SOMETHING SLIGHTLY DIFFERENT.

LISTENING TO WARWICK ANDERSON AND ALZHEIMER'S AUSTRALIA'S CEO GLENN REES, TALK ABOUT THIS THE OTHER WEEK I WAS LEFT QUITE PUZZLED AS THE TERM KT WAS BANDIED ABOUT.

I ASKED MYSELF WHO WAS IN CONTROL OF KT. THE CONSUMER? THE CLINICIAN AND SERVICE PROVIDER? OR THE RESEARCHER? MORE PUZZLING STILL LISTENING TO THAT ERUDITE DISCUSSION WAS WHERE DID KT BEGIN AND END?

IT IS OBVIOUS ENOUGH THAT AN EVIDENCE BASE IS NEEDED AND THAT IT SHOULD BE USED TO INFORM PRACTICE AND THAT SOMEONE NEEDS TO DECIDE WHAT THE PRIORITIES ARE FOR THIS ACTIVITY.

WHAT'S NOT OBVIOUS IS WHO SHOULD BE DRIVING THE WORK? THERE APPEARS TO BE DIFFERENT SCHOOLS OF THOUGHT.

CONSUMERS THINK HEALTH OUTCOMES ARE ABOUT THEM AND THAT THEY SHOULD BE INVOLVED FROM THE START. THE PHRASE CONSUMERS OFTEN USE IS “NOTHING ABOUT ME WITHOUT ME”.

INDEED THEY MIGHT BE SO BOLD AS TO BELIEVE THAT THEY SHOULD SET THE PRIORITIES FOR KT ON THE BASIS OF WHAT CONCERNS THEM MOST IN THE DELIVERY OF HEALTH AND CARE SERVICES.

AT THE OTHER EXTREME ARE THE RESEARCHERS WHO PRODUCE THE EVIDENCE BASE AND HAVE A STRONG VIEW ABOUT ITS VALIDITY AND TRANSLATABILITY.

SOMEWHERE IN THERE FIGHTING FOR A PLACE IN KT IS THE CLINICIAN AND SERVICE PROVIDER WHO NO DOUBT BELIEVE THEY’RE DOING A GOOD JOB AND HAVE INNOVATIVE APPROACHES TO CARE AND SERVICES THAT ARE WORKING WELL.

THEY MAY BE RELUCTANT TO WAIT FOR PEER REVIEWED ARTICLES OR FOR A SCIENTIST TO ARRIVE TO TELL THEM WHAT GOOD PRACTICE IS. SO WHY CHANGE?

OVER THE YEARS IN THIS BATTLE FOR LEADERSHIP THE RESULT HAS BEEN THAT EACH GROUP HAS FOCUSED ON WHAT THEY KNOW BEST. THERE HAS BEEN A TRAGIC FAILURE TO ACTUALLY GET INTO PRACTICE THE EVIDENCE THAT MIGHT MAKE A DIFFERENCE TO PEOPLE'S LIVES.

CONVENTIONAL WISDOM SUGGESTS THAT IT TAKES 17 YEARS TO GET RESEARCH INTO PRACTICE.

IN SHORT THE NHMRC AND ALZHEIMER'S AUSTRALIA ARE STARTING FROM THE OPPOSITE ENDS OF THE STICK AND OF COURSE, BOTH MIGHT BE RIGHT.

LET'S START WITH THE NHMRC. THE RESEARCH TRANSLATION FACULTY WAS OFFICIALLY LAUNCHED NEARLY A YEAR AGO AS THE GOVERNMENT SECTOR MOVED TO CLOSE THE GAP BETWEEN RESEARCH AND PRACTICE.

MORE THAN 2,800 NHMRC SUPPORTED CHIEF INVESTIGATORS AND FELLOWSHIP HOLDERS HAVE JOINED THE FACULTY. FOURTEEN STEERING GROUPS HAVE BEEN SET UP FOR MAJOR HEALTH ISSUES INCLUDING DEMENTIA.

FROM ALZHEIMER'S AUSTRALIA'S PERSPECTIVE THIS WAS A POSITIVE DEVELOPMENT. WE LOOK FORWARD TO SEEING THE PRIORITIES THAT THESE GROUPS WILL DEVELOP.

THE COMMUNITY AND CONSUMER ADVISORY GROUP IS ANOTHER NEW LAYER OF THE NHMRC TO SUPPORT THE TRANSLATION OF RESEARCH.

BOTH THE FACULTY AND THE ADVISORY GROUP FORM PART OF A SYSTEM THAT THE NHMRC CALLS THE 'VIRTUOUS CYCLE', WHICH DEPICTS THE GOVERNMENT AND THE COMMUNITY INVESTING IN RESEARCH; RESEARCH BEING PERFORMED AND FINALLY RESEARCH BEING TRANSLATED FOR THE BENEFIT OF THE COMMUNITY.

THE NEXT STAGE WILL BE FOR EACH OF THE GROUPS TO IDENTIFY A PRIORITY WHICH WILL THEN BE DISCUSSED WITH OTHER STAKEHOLDERS AND SOME ACTION DETERMINED.

THIS IS A GREAT MODEL FOR PRE-EXISTING RESEARCH AND MAY ALSO IDENTIFY GAPS. THE GOVERNMENT AND THE COMMUNITY HAVE FUNDED THE KNOWLEDGE AND THEREFORE SHOULD REAP THE BENEFITS.

THERE IS ALREADY A LOT OF INFORMATION LOCKED AWAY IN SCIENTIFIC PAPERS JUST WAITING TO BE TRANSFORMED INTO USEABLE PROGRAMS AND ADVANCEMENTS.

AS AN ADVOCACY ORGANISATION, ALZHEIMER'S AUSTRALIA TAKES A DIFFERENT APPROACH. WE START WITH CONSUMER CONCERNS ABOUT HEALTH AND CARE OUTCOMES IN ORDER TO SET PRIORITIES.

TO ACHIEVE THIS WE HAVE ESTABLISHED A CONSUMER DEMENTIA RESEARCH NETWORK, A PANEL OF 27 PEOPLE WITH DEMENTIA, OR WHO ARE PRESENT OR FORMER CARERS. THEY COME FROM ALL OVER AUSTRALIA.

THE NETWORK HAS DRIVEN ALZHEIMER'S AUSTRALIA'S OWN NATIONAL QUALITY DEMENTIA CARE INITIATIVE WHICH HAS COMMITTED \$3 MILLION TO HIGHLY TARGETED KNOWLEDGE TRANSLATION PROJECTS, THANKS TO THE GENEROUS SUPPORT OF THE J.O. AND J.R. WICKING ANZ TRUST AND BUPA CARE SERVICES.

EACH PROJECT WE FUND ADDRESSES PRIORITIES IDENTIFIED BY CONSUMERS, WHO ALSO MAKE THE FINAL DECISIONS ON FUNDING FOR COLLABORATIVE PROJECTS THAT USE INNOVATIVE APPROACHES TO ACHIEVE SUSTAINABLE AND NATIONAL CHANGES IN DEMENTIA CARE.

IT'S EARLY DAYS BUT ALREADY THE PROJECTS ARE SHOWING RESULTS.

THE DEMENTIA DESIGN PROJECT FOR CONSUMERS' HOME MODIFICATIONS IS BEING ROLLED OUT NATIONALLY. DEMENTIA DESIGN UNITS HAVE BEEN INCLUDED IN SEVERAL UNIVERSITY COURSES AND THERE IS NOW THE FIRST INCLUSION OF DEMENTIA IN AUSTRALIAN DESIGN STANDARDS.

NATIONAL WORKSHOPS ARE BEING ROLLED OUT TO BUILD UP THE SKILLS OF PEOPLE WITH DEMENTIA AND TO ENGAGE THEM USING MONTESSORI METHODS FOR FAMILY AND RESIDENTIAL CARERS.

WHETHER YOU START WITH RESEARCHERS, SERVICE PROVIDERS OR CONSUMERS, TEAM WORK IS THE CRITICAL FACTOR. AND THE MIX OF SKILLS NEEDED GOES FAR BEYOND EVIDENCE TO AN UNDERSTANDING OF THE MULTIPLE MEANS OF IMPLEMENTING KT – INCLUDING TRAINING, FINANCIAL INCENTIVES, REGULATORY ACTION AND CLINICAL GUIDELINES.

BOTH ALZHEIMER'S AUSTRALIA AND THE NHMRC HAVE REALISED THE IMPORTANCE OF PARTNERSHIPS AND WORKING TOGETHER AND EVEN IF WE ARE TAKING DIFFERENT PATHS HOPEFULLY WE WILL BOTH ACHIEVE IMPROVED CARE AND SERVICES.

THE BIGGEST PRIZE OF ALL THOUGH HAS TO BE PUBLIC POLICY INFORMED BY RESEARCH. THIS IS AN AREA WHERE ALZHEIMER'S AUSTRALIA HAS HAD SOME SUCCESS.

A GOOD ILLUSTRATION IS THE WORK WE'VE DONE IN TRANSLATING RESEARCH INTO BETTER DEMENTIA CARE IN HOSPITALS.

AT THE START, WE HAD ANECDOTAL REPORTS AND OBSERVATIONS OF PEOPLE WITH DEMENTIA WHO WERE CLEARLY RECEIVING SUBSTANDARD ACUTE CARE. HORROR STORIES OF PEOPLE WITH DEMENTIA NOT GETTING ADEQUATE NUTRITION BECAUSE NO ONE THOUGHT TO ASSIST THEM AT MEAL TIMES; STORIES OF PEOPLE BECOMING MORE CONFUSED AND AGITATED BECAUSE OF THE LACK OF APPROPRIATE CARE.

WITH THE SUPPORT OF THE MINISTER'S DEMENTIA ADVISORY GROUP AND THE COMMONWEALTH DEPARTMENT OF HEALTH, A STAKEHOLDER MEETING WAS ORGANISED TO DISCUSS THE ISSUES AND MAKE RECOMMENDATIONS FOR ACTION.

TO COMPLEMENT THAT WORK, ALZHEIMER'S AUSTRALIA COMMISSIONED AN ECONOMIC ANALYSIS OF THE COSTS OF DEMENTIA CARE IN HOSPITALS FROM THE AUSTRALIAN INSTITUTE OF HEALTH AND WELFARE, WITH SUPPORT FROM THE J.O. AND J.R. WICKING TRUST.

**WE NOW HAVE THE OUTCOME OF MORE THAN FIVE YEARS HARD WORK
I AM PLEASED TO SAY THAT THE *LIVING LONGER, LIVING BETTER* AGED
CARE REFORM PACKAGE ANNOUNCED LAST YEAR INCLUDED MORE THAN
\$40 MILLION TO IMPROVE HOSPITAL SERVICES FOR PEOPLE WITH
DEMENTIA.**

**AND AS A CONSEQUENCE THE AUSTRALIAN COMMISSION ON SAFETY AND
QUALITY IN HEALTHCARE HAS BEGUN THE PROCESS OF WRITING
DEMENTIA CARE INTO THE MANDATORY STANDARDS APPLYING TO ALL
HOSPITALS.**

**ALZHEIMER'S AUSTRALIA IS NOT AN EXPERT ON HOSPITALS BUT WE HAVE
BEEN ABLE TO USE OUR CONSUMER MANDATE AND POSITION AS AN
IMPARTIAL, NATIONAL ORGANISATION TO ACT AS A COORDINATOR OF
THESE EFFORTS...A SORT OF SPIDER IN THE WEB, BRINGING TOGETHER
THE MANY STRANDS REQUIRED FOR SUCCESSFUL OUTCOMES.**

ANOTHER AREA OF OUR WORK OF WHICH I AM ESPECIALLY PROUD IS CONSUMER DIRECTED CARE. WE BELIEVE CONSUMERS SHOULD DIRECT THEIR OWN CARE NEEDS WITHIN THE FUNDING AVAILABLE TO THEM, ON AN INDIVIDUAL BASIS.

WE HAVE WORKED WITH AUSTRALIAN AND INTERNATIONAL RESEARCHERS FOR 12 YEARS TO PULL TOGETHER OUR EVIDENCE BASE FOR CONSUMER DIRECTED CARE.

WE HELD WORKSHOPS NATIONALLY AND SPOKE AT CONFERENCES AND THEN TOOK OUR EVIDENCE TO THE MINISTERIAL AND DEPARTMENTAL ADVISORY COMMITTEES. CONSUMER DIRECTED CARE IS NOW PART OF THE NEW AGED CARE REFORMS AND I SHOULD ADD THAT THIS WAS DONE IN PARTNERSHIP WITH MANY OTHERS.

WE HAVE BEEN COLLECTING THE EVIDENCE SINCE 2006 TO SHOW THAT IT MIGHT BE POSSIBLE TO LOWER PEOPLE'S RISK OF DEMENTIA.

LAST YEAR, AUSTRALIA BECAME THE FIRST COUNTRY IN THE WORLD TO HAVE A PUBLICALLY FUNDED DEMENTIA RISK REDUCTION PROGRAM.

***YOUR BRAIN MATTERS* IS A FANTASTIC RESOURCE AND A PROGRAM THAT IS GAINING AN INCREASING INTEREST.**

PEOPLE DON'T WANT TO HEAR ABOUT A HORRIBLE DISEASE THAT THEY CAN'T DO ANYTHING TO AVOID. WITHOUT CREATING FALSE EXPECTATIONS IT IS IMPORTANT AUSTRALIANS UNDERSTAND THAT THEY MAY BE ABLE TO REDUCE THEIR RISK OF DEMENTIA. THIS LINE OF THINKING GIVES PEOPLE A SENSE OF CONTROL AND HELPS CREATE ROOM FOR OPEN DISCUSSION IN THE COMMUNITY.

WE'VE LEARNED THAT IN ORDER TO TRANSLATE RESEARCH INTO PUBLIC POLICY WE MUST DO MORE THAN SIMPLY LEAVE ALL OF THE RESPONSIBILITY TO OUR RESEARCHERS.

IN ORDER TO MAKE THE MOST OF YOUR UNMATCHED KNOWLEDGE, DEDICATION AND SKILLS, WE MUST ENSURE THAT THE SKILLS WE HAVE IN ADVOCACY, TRAINING AND COMMUNICATION ARE IN PLACE TO HELP.

IT IS IMPORTANT THAT CONSUMERS AND HEALTHCARE PROVIDERS ARE INVOLVED WITH RESEARCHERS THROUGHOUT THE PROCESS, AND CONTRIBUTE TO THE FORMULATION, THE PRIORITISATION, THE CONDUCT AND THE DISSEMINATION OF HEALTH AND MEDICAL RESEARCH.

ALZHEIMER'S AUSTRALIA IS PLEASED TO BE INVOLVED AS A FUNDING PARTNER WITH THREE OTHER NGOS ALONGSIDE THE NHMRC IN AUSTRALIAN'S FIRST PARTNERSHIP CENTRE FOR COGNITIVE DECLINE. IN TOTAL \$25 MILLION HAS BEEN COMMITTED BY NHMRC AND THE PARTNERS TO THE CENTRE.

WE COMMITTED TO THIS PROJECT BECAUSE IT HAS THE POTENTIAL TO PROMOTE COLLABORATION BETWEEN RESEARCHERS, CLINICIANS, AGED CARE SERVICE PROVIDERS AND CONSUMERS, AND TO INTEGRATE RELEVANT EVIDENCE INTO HEALTH AND AGED CARE SERVICES IN WAYS THAT BENEFIT OLDER PEOPLE WITH COGNITIVE DECLINE.

THE ALZHEIMER'S AUSTRALIA CONSUMER DEMENTIA RESEARCH NETWORK WILL BE CENTRALLY INVOLVED IN THE WORK OF THE CENTRE ACROSS ALL OF ITS PRIORITIES.

IMPORTANTLY, THE PARTNERSHIP CENTRES (THERE ARE NOW TWO AND I BELIEVE TWO OR THREE OTHERS ARE PLANNED) ARE *NOT* PRIMARILY RESEARCH CENTRES, AND FOR THIS BOLD STEP I CONGRATULATE WARWICK ANDERSON AND THE NHMRC. THIS IS TRULY GOING TO BE KNOWLEDGE TRANSLATION IN ACTION.

THERE IS A HOST OF OTHER CENTRES AND INITIATIVES IN THE DEMENTIA SECTOR SUCH AS THE DEMENTIA COLLABORATIVE RESEARCH CENTRES; THE WICKING DEMENTIA RESEARCH AND EDUCATION CENTRE; THE TEACHING AND RESEARCH IN AGED CARE PROGRAM; THE EVIDENCE BASED PRACTICE IN AGED CARE INITIATIVE; ALONG WITH MANY OTHERS IN OTHER HEALTH RESEARCH AREAS

THESE ARE GOOD BEGINNINGS, HOWEVER AS I'M SURE YOU'LL AGREE, WE STILL NEED TO DO MORE.

THERE IS MUCH TO LOOK FORWARD TO IN THE NEXT FEW YEARS SUCH AS THE IMPLEMENTATION OF THE \$200 MILLION OVER FIVE YEARS FOCUSED ON DEMENTIA RESEARCH; THE PROSPECT OF FOSTERING COLLABORATION IN THE IMPLEMENTATION OF KNOWLEDGE TRANSLATION;

THERE IS ALSO MUCH TO CELEBRATE IN THE MANY DIFFERENT APPROACHES BEING TRIED WHETHER IT IS THE FACULTY, THE JOINT CENTRE OR THE NATIONAL QUALITY DEMENTIA CARE INITIATIVE.

OF ONE THING WE CAN BE CERTAIN. IF WE ARE TO BE MORE SUCCESSFUL IN TURNING THE FRUITS OF RESEARCH INTO BETTER QUALITY HEALTH AND CARE OUTCOMES WE WILL NEED ALL THE INGENUITY AT OUR DISPOSAL AS WELL AS A GENUINE COMMITMENT TO TEAMWORK.

WE CAN ACHIEVE SO MUCH TOGETHER....AND LET ME ASSURE YOU, ALZHEIMER'S AUSTRALIA IS 100 PER CENT COMMITTED TO THIS GOAL.

THANK YOU.

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