

CATHOLIC HEALTH NATIONAL CONFERENCE

TOGETHER TOWARDS TOMORROW

DEMENTIA: THE GLOBAL SCENE AND LESSONS FOR AUSTRALIA

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MY SINCERE THANKS TO CATHOLIC HEALTH AUSTRALIA FOR THE INVITATION TO SPEAK TO YOU DAY AS CHAIR OF ALZHEIMER'S DISEASE INTERNATIONAL (ADI).

OVER THE YEARS I HAVE HAD THE BENEFIT OF WORKING CLOSELY WITH CHA. I HAVE MUCH ADMIRER YOUR COMMITMENT TO ACHIEVING IMPROVED CONSUMER OUTCOMES IN HEALTH AND AGED CARE.

VALUES AND PHILOSOPHY ARE KEY TO ACHIEVING CHANGE AND WINNING HEARTS AND MINDS AND THIS IS WHY CATHOLIC HEALTH AUSTRALIA HAS SUCH A KEY ROLE TO PLAY.

MY ROLE IS TO SET THE SCENE AT THE GLOBAL LEVEL ON DEMENTIA AND THE LESSONS IT MAY HOLD FOR AUSTRALIA.

AFTER PROVIDING AN OVERVIEW OF WHAT IS HAPPENING AT THE GLOBAL LEVEL I WILL DISCUSS

- WHAT AUSTRALIA NEEDS TO DO IN RE-SHAPING ITS STRATEGIC APPROACH TO DEMENTIA
- SPECIFIC INITIATIVES OF INTEREST IN HEALTH AND AGED CARE.
- THE IMPORTANCE OF SOCIAL ACTION THROUGH DEMENTIA FRIENDLY SOCIETIES AND ORGANISATIONS

OVERVIEW

WE CAN I THINK BE CAUTIOUSLY OPTIMISTIC ABOUT 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.

I REMAIN OF THE VIEW I HAVE HELD FOR MANY YEARS THAT ACTION ON DEMENTIA AT THE GLOBAL AND LOCAL LEVEL REQUIRES REVOLUTION AND NOT EVOLUTION. AND THAT THE DRIVING FORCE WILL HAVE TO COME FROM CIVIL SOCIETY AND IN PARTICULAR FROM ALZHEIMER'S ORGANISATIONS AND ORGANISATIONS LIKE CATHOLIC HEALTH AUSTRALIA.

SO WHAT ARE THE DRIVERS OF CHANGE AT THE GLOBAL LEVEL?

FIRST, THE ESTABLISHMENT OF AN EVIDENCE BASE. WE KNOW 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. THESE WILL BE SHOWN TO BE A GROSS UNDERESTIMATE IN A REPORT LATER THIS WEEK.
- 60 PER CENT OF THE DISEASE BURDEN FALLS ON LOW AND MIDDLE INCOME COUNTRIES.

SECOND, THERE HAS BEEN A CHANGE IN LANGUAGE THAT EMBRACES DEMENTIA AS A PUBLIC HEALTH ISSUE, AS A CHRONIC DISEASE, AS PREVENTABLE AND AS A SOCIAL AS WELL AS A MEDICAL ISSUE.

AUSTRALIA HAS BEEN A LEADER IN PROMOTING THE MESSAGE ABOUT THE PREVENTION OF DEMENTIA THROUGH THE YOUR BRAIN MATTERS PROGRAM. SADLY THE FEDERAL FUNDING THE PROGRAM HAS BEEN TERMINATED. HOPEFULLY IT WILL BE RENEWED AT A FUTURE TIME.

THIRD, THE MULTIPLICITY OF CHANNELS THROUGH WHICH TO PROSECUTE THE ISSUE OF DEMENTIA INCLUDING:

- THE WORLD HEALTH ORGANISATION AND THE RECENT MINISTERIAL DEMENTIA MEETING WHICH RESULTED IN A DECLARATION
- THE WORLD DEMENTIA COUNCIL ESTABLISHED BY THE G7
- THE WORK OF THE ORGANISATION FOR ECONOMIC COOPERATION AND DEVELOPMENT ON THE QUALITY OF DEMENTIA CARE
- THE NON COMMUNICABLE DISEASE ALLIANCE IN ESTABLISHING A BASIS FOR COOPERATION ON PREVENTION ACROSS THE MAJOR CHRONIC DISEASES
- UNITED NATIONS WORK ON THE RIGHTS OF ELDERLY PEOPLE AND PEOPLE WITH DISABILITIES

THE OBJECTIVE OF ADI IS TO SUSTAIN THIS MOMENTUM BY A RESOLUTION ON DEMENTIA AT THE NEXT WHO WORLD HEALTH ASSEMBLY IN 2016.

FOURTH, THE PRIORITY GIVEN AT THE GLOBAL LEVEL TO THE IMPORTANCE OF DEMENTIA RESEARCH FUNDING.

DEMENTIA RESEARCH DESPITE RECENT INCREASES IN FUNDING REMAINS GROSSLY UNDERFUNDED IN RELATION TO CANCER, HIV-AIDS AND CARDIO-VASCULAR DISEASE – OECD ESTIMATES DEMENTIA ACCOUNTS FOR 0.8% OF PUBLIC FUNDING ON RESEARCH AND DEVELOPMENT.

ON THIS AUSTRALIA HAS LEAD BY EXAMPLE WITH A COMMITMENT TO AN ADDITIONAL \$200 MILLION OVER 5 YEARS.

SO HAVING GOT TO THE POINT OF CAUTIOUS OPTIMISM ABOUT PROGRESS AT THE GLOBAL LEVEL WHAT STRATEGIC LESSONS CAN AUSTRALIA LEARN?

STRATEGIC APPROACH

AUSTRALIA CAN BE PROUD OF BEING THE FIRST COUNTRY IN THE WORLD TO ACKNOWLEDGE DEMENTIA AS A MAJOR HEALTH ISSUE.

IN THE 2004 FEDERAL BUDGET \$320 MILLION WAS COMMITTED TO FUND THE DEMENTIA INITIATIVE OVER FIVE YEARS TO PROVIDE TRAINING, RESEARCH, EXTENDED AGED CARE AT HOME DEMENTIA PACKAGES AND INCREASED SUPPORT FOR INFORMATION AND SERVICES THROUGH ALZHEIMER'S AUSTRALIA.

AND THERE WAS AN IMPORTANT COMMITMENT TO TACKLE DEMENTIA IN THE 2012 AGED CARE REFORMS.

THERE ARE NOW 20 COUNTRIES WITH CARE PLANS IN PLACE WITH VARYING DEGREES OF COMPREHENSIVENESS. AND BY THE END OF THE YEAR ADI IS HOPING THERE WILL BE AT LEAST 25 PLANS.

THESE PLANS ARE THE PRE-CONDITION FOR POLITICAL AWARENESS AND FUTURE ACTION.

IN 2015 THE ORGANISATION FOR ECONOMIC COOPERATION AND DEVELOPMENT PUBLISHED **ADDRESSING DEMENTIA** WHICH PROVIDES AN OVERVIEW OF POLICIES EMPLOYED BY MEMBER COUNTRIES TO TACKLE DEMENTIA. THE PICTURE THEY DRAW IS THIS. MOST OF THE POLICIES REPORTED UPON HAVE THEIR COUNTERPARTS IN AUSTRALIA.

OECD CONCLUDES THAT ENSURING THAT THE CONSISTENT IMPLEMENTATION OF THESE POLICIES REMAINS A CHALLENGE AND THAT THERE IS STILL TOO MUCH UNCERTAINTY AROUND WHICH POLICIES ARE EFFECTIVE.

I THINK THIS APPLIES EQUALLY TO AUSTRALIA.

THE AUSTRALIAN NATIONAL FRAMEWORK FOR ACTION ON DEMENTIA TERMINATED IN 2010. I UNDERSTAND COMMONWEALTH AND STATE HEALTH MINISTERS HAVE A REVISED DRAFT FRAMEWORK UNDER CONSIDERATION.

WE NEED IS A PLAN THAT COMMITS TO

- DEMENTIA RISK REDUCTION
- IMPROVES THE RATE OF THE DIAGNOSIS OF DEMENTIA
- MAKING COMMUNITIES FRIENDLIER PLACES FOR PEOPLE WITH DEMENTIA
- EXPANDED COMMUNITY CARE WITH A PRIORITY FOR FLEXIBLE DEMENTIA RESPITE
- SAFE AND HIGH QUALITY LONG TERM RESIDENTIAL CARE SERVICES
- THE EFFECTIVE MANAGEMENT OF PEOPLE WITH DEMENTIA IN HOSPITALS
- END OF LIFE CARE FOR PEOPLE WITH DEMENTIA THAT GIVES THEM THE RIGHT TO DIE WITH DIGNITY IN A PLACE OF THEIR CHOOSING

THE NEED IS TO ACHIEVE SYSTEMIC CHANGE. WE HAVE THE OPPORTUNITY IN AUSTRALIA TO MAKE PROGRESS IN TERMS OF A NATIONAL AGED CARE PROGRAM AND THE POLICY EMPHASIS ON PERSON CENTRED CARE, CONSUMER DIRECTED CARE AND EXPANDED COMMUNITY CARE.

BUT HEALTH REMAINS MORE PROBLEMATIC. THERE IS THE COMMITMENT IN THE 2012 AGED CARE REFORMS TO PROVIDE \$26 MILLION FOR TIMELY DIAGNOSIS AND \$40 MILLION TO ENHANCE HOSPITAL SERVICES.

WITH THE TRANSFER OF THIS FUNDING TO DSS IT HAS BECOME INCREASINGLY UNLIKELY THAT THIS FUNDING WILL BE USED CREATIVELY TO ACHIEVE SYSTEMIC CHANGES IN THE HEALTH SYSTEM EVEN THOUGH SOME WORTHWHILE PROJECTS HAVE BEEN FUNDED, NOTABLY THE PRODUCTION BY THE OF THE AUSTRALIAN COMMISSION ON SAFETY AND QUALITY IN HEALTH CARE ***A BETTER WAY TO CARE: SAFETY AND QUALITY FOR PATIENTS WITH COGNITIVE IMPAIRMENT (DEMENTIA AND DELIRIUM) IN HOSPITAL*** AND TRAINING OF DOCTORS

THE FLEXIBLE FUNDS INTRODUCED IN 2011 ARE NOT HELPFUL TO TRANSPARENCY OR PLANNING AND MAKE IT NEXT TO IMPOSSIBLE TO BUILD ON THE DEMENTIA INITIATIVE OF THE HOWARD GOVERNMENT AND THE 2012 AGED CARE REFORMS IN USING THE FUNDING PROVIDED TO IMPROVE DEMENTIA CARE.

SO KEEPING IN MIND THE NEED FOR SYSTEMIC CHANGE PARTICULARLY IN HEALTH WHAT CAN AUSTRALIA LEARN FROM OVERSEAS?

HEALTH AND AGED CARE POLICY

I HAVE SELECTED FOUR AREAS:

- THE TIMELY DIAGNOSIS OF DEMENTIA AND POST DIAGNOSTIC SUPPORT
- THE DEVELOPMENT OF FLEXIBLE RESPITE CARE
- IMPROVING THE CARE OF PEOPLE WITH DEMENTIA IN ACUTE CARE
- QUALITY STANDARDS IN COMMUNITY AND RESIDENTIAL CARE

a) Timely diagnosis and post diagnostic support

ADI HAS ESTIMATED THAT CURRENTLY LESS THAN HALF OF THE PEOPLE WITH DEMENTIA IN HIGH INCOME COUNTRIES HAVE RECEIVED A DIAGNOSIS, AND FEWER THAN 10% OF PEOPLE WITH DEMENTIA IN LOW TO MIDDLE INCOME COUNTRIES. THIS MEANS MORE THAN 22 MILLION PEOPLE LIVING WITH DEMENTIA DO NOT HAVE ACCESS TO INFORMATION, CARE AND TREATMENT.

IN AUSTRALIA IT IS ESTIMATED THAT ONLY A THIRD OF PEOPLE WHO HAVE DEMENTIA RECEIVE A DIAGNOSIS AT ANY TIME IN THEIR ILLNESS. FOR THOSE WHO ARE DIAGNOSED, MANY DO NOT RECEIVE A DIAGNOSIS UNTIL THREE YEARS AFTER THEY FIRST NOTICE SYMPTOMS.

TIMELY DIAGNOSIS IS A FOCUS FOR DEVELOPING NATIONAL DEMENTIA STRATEGIES IN EUROPE, SOUTH KOREA, JAPAN AND TAIWAN.

SCOTLAND HAS TACKLED THIS PROBLEM HEAD ON IN THE MOST INTERESTING WAY AND HAS INCREASED THE RATE OF DIAGNOSIS TO ABOUT 60 PER CENT. TWO STRATEGIES HAVE BEEN EMPLOYED.

FIRST, TO SET A HEALTH EQUITY ACCESS TARGET WHICH CAN BE INCREASED OVER TIME AND IS MONITORED AS A SYSTEM OUTCOME BY THE HEALTH AUTHORITIES.

SECOND, IS A POST DIAGNOSTIC SUPPORT GUARANTEE WHICH GIVES THE PERSON WITH A DIAGNOSIS A GUARANTEE OF SUPPORT FROM A NAMED DEMENTIA LINK WORKER FOR 12 MONTHS.

THE ATTRACTION OF THIS FROM A CONSUMER VIEWPOINT IS THAT IT REDUCES TO FEAR OF SEEKING A DIAGNOSIS BECAUSE IT GIVES AN ASSURANCE OF SUPPORT.

THE OBJECTIVE IS TO DEVELOP A ROBUST PERSONAL PLAN THAT UTILISES ALL THE INDIVIDUAL'S NETWORKS ALONGSIDE

NEW COMMUNITY SUPPORT TO ENABLE EACH PERSON TO LIVE WELL AND INDEPENDENTLY WITH DEMENTIA FOR AS LONG AS POSSIBLE.

THE MODEL HAS THE POTENTIAL TO BE PARTICULARLY ATTRACTIVE FOR THOSE LIVING ALONE - AN ISSUE THAT IS OF CONCERN IN AUSTRALIA.

THE SUPPORT IS PROVIDED BY A TRAINED DEMENTIA LINKWORKER WHO FUNCTIONS AS A MEMBER OF THE COMMUNITY MENTAL HEALTH TEAM.

THIS MODEL AND THE SCOTTISH APPROACH TO PLANNING MAKES TRANSPARENT FOR THE CONSUMER WHAT THEY ARE ENTITLED TO, ENSURES CO-ORDINATION OF SERVICES AND LAYS THE BASIS FOR RELATING SERVICES AND SUPPORT IN AN EFFICIENT WAY TO THE NEEDS OF THE INDIVIDUAL.

THE FIRST LINK PROGRAM IN CANADA SHARES SIMILAR OBJECTIVES AND HAS BEEN EVALUATED.

IN AUSTRALIA CONSUMERS HAVE FOR YEARS ADVOCATED AS A TOP PRIORITY FOR DEMENTIA KEY WORKERS TO PROVIDE AN ONGOING POINT OF CONTACT FOR INFORMATION, ADVICE AND SUPPORT. SADLY THE ONLY FUNDING IN PLACE FOR DEMENTIA KEY WORKERS AS A CONSEQUENCE OF THE 2012 REFORMS IS FOR YOUNGER PEOPLE WITH DEMENTIA AND THAT MAY BE TERMINATED.

b) Respite Care

RESPITE CARE IN MY VIEW SHOULD RECEIVE A MUCH HIGHER PRIORITY IN DEMENTIA CARE POLICY. IT IS THE MOST DEMANDED SERVICE BY AUSTRALIAN FAMILY CARERS OF PEOPLE WITH DEMENTIA AND WELL DESIGNED RESPITE CAN SOCIALLY ENGAGE THE PERSON WITH DEMENTIA.

THE JAPANESE ARE SHOWING US THE WAY. I AM GRATEFUL TO DR MAYUMI HAYASHI FOR PROVIDING THE FOLLOWING INFORMATION.

THE JAPANESE INTRODUCED MICRO MULTI FUNCTIONAL COMMUNITY CARE FACILITIES IN 2006 UNDER THE REFORM TO THE NATIONAL LONG TERM CARE INSURANCE (LTCI) SYSTEM. THERE ARE NOW 4,000 FACILITIES ACROSS JAPAN SUPPORTING 76,000 SERVICE USERS – THE MAJORITY BEING PEOPLE WITH DEMENTIA. EACH FACILITY PROVIDES FOR 25 PEOPLE. THE CARE PACKAGE WITHIN THE FACILITY IS COMPREHENSIVE, INCLUDING:

- 24/7/365 ALL ROUND OPEN ACCESS
- DAY CARE SERVICES
- FLEXIBLE 24 HOUR RESPITE CARE
- REGULAR AND ON-DEMAND HEALTH CARE BY NURSES
- REGULAR AND ON-DEMAND HOME CARE BY CARE WORKERS.

THIS MODEL SUPPORTS USERS TO REMAIN IN THE COMMUNITY AND AVOID MORE EXPENSIVE RESIDENTIAL CARE. ITS AIM IS TO PROVIDE A SEAMLESS SERVICE WITH CONSISTENCY AND CONTINUITY.

DEMENTIA DAY CENTRES ARE ANOTHER ENDORSED LTCI COMMUNITY-BASED MODEL SUPPORTING UP TO 12 PEOPLE. OPEN THROUGHOUT THE YEAR, THESE DEMENTIA SPECIFIC DAY CENTRES OFFER 7 OR 9 HOUR DAILY SESSIONS FOR PEOPLE AT ALL STAGES OF THE DISEASE PROCESS.

THEY HAVE A FAMILY RATHER THAN INSTITUTIONAL ETHOS AND ARE ALSO SET IN RESIDENTIAL AREAS. THESE DEMENTIA DAY CENTRES OFFER ENGAGING ACTIVITIES WHICH ARE PERSON CENTRED AND ATTUNED TO INDIVIDUAL NEEDS AND PREFERENCES. THEY ARE STAFFED BY SKILLED CARE WORKERS RATHER THAN HIGHLY QUALIFIED OCCUPATIONAL THERAPISTS AND PSYCHOLOGISTS.

THERE ARE 3,800 SUCH DEMENTIA DAY CENTRES SUPPORTING 61,000 PEOPLE WITH DEMENTIA. SOME CENTRES WORK ON COGNITIVE THERAPY AND RESTORING CAPACITY.

JAPAN HAS 35,500 GENERIC DAY CENTRES (FOR OLDER PEOPLE) SUPPORTING 1.6 MILLION – OR 1 IN 3 ELIGIBLE OLDER PEOPLE, THE WORLD'S HIGHEST PER CAPITA. THESE ATTENDANCE AND USAGE FIGURES DO OF COURSE INCLUDE MANY WHO ARE LIVING WITH DEMENTIA.

THE MODELS ARE COMBINED WITH OTHER ENLIGHTENED APPROACHES LIKE PROMOTING INTERGENERATIONAL INTERACTION THAT BRING TOGETHER LTCI FUNDED PROVISION WITH PUBLIC FUNDED FACILITIES FOR THE YOUNGER GENERATION

WHILE I AM DREAMING LET ME ASSURE YOU THAT I HAVE LOST NONE OF MY ENTHUSIASM FOR PUTTING CASH IN THE HANDS OF CONSUMERS AS ANOTHER APPROACH TO ACHIEVING FLEXIBILITY IN RESPITE. A MODEL TO ACHIEVE THIS COMBINED WITH AN EXPANSION OF SERVICES ON THE LINES OF WHAT THE JAPANESE HAVE WOULD GIVE REALITY TO CHOICE FOR OLDER PEOPLE AND PEOPLE WITH DEMENTIA.

c) Acute Care

ACROSS THE WORLD ACUTE CARE SYSTEMS ARE STRUGGLING TO CARE FOR PEOPLE WITH DEMENTIA. FOR EXAMPLE, ALREADY A QUARTER OF HOSPITAL BEDS IN THE UK ARE OCCUPIED BY PEOPLE WITH DEMENTIA AND MANY OF THESE PEOPLE ARE NOT RECEIVING CARE THAT MEETS THEIR NEEDS.

INTERNATIONAL STUDIES HAVE SHOWN THAT PEOPLE WITH DEMENTIA STAY IN HOSPITAL ALMOST TWICE AS LONG AS THOSE WITHOUT DEMENTIA AND INVARIABLY HAVE WORSE CLINICAL OUTCOMES. FOR EXAMPLE, THEY ARE TWICE AS LIKELY TO EXPERIENCE FALLS, PRESSURE ULCERS, FRACTURES AND DELIRIUM.

SOME OF THESE DIFFERENCES ARE TO BE EXPECTED DUE TO THE NATURE OF THE DISEASE, BUT WITH BETTER CARE, COMMUNICATION AND DESIGN, OUTCOMES FOR PEOPLE WITH DEMENTIA COULD BE SIGNIFICANTLY IMPROVED IN HOSPITALS. THE UK IS ONE OF THE FEW PLACES THAT HAS PRIORITISED IMPROVING DEMENTIA CARE IN HOSPITALS, INCLUDING DEVELOPING AND IMPROVING ALTERNATIVES TO HOSPITAL ADMISSION.

THE SCOTS HAVE TAKEN THIS STRATEGY TO A NEW LEVEL – BELIEVE ME I DO NOT WORK FOR THE SCOTTISH TOURIST BOARD BUT I DO OWE ALZHEIMER’S SCOTLAND A LOT FOR GIVING ME SO MUCH OF THEIR TIME!

DEMENTIA CARE IN ACUTE GENERAL HOSPITALS HAS BEEN A KEY FOCUS IN BOTH THE FIRST AND SECOND NATIONAL DEMENTIA STRATEGIES IN SCOTLAND. THE APPROACH IS COMPREHENSIVE INCLUDING INITIALLY A FOCUS ON A LEADERSHIP STRUCTURE WITHIN NHS BOARDS TO DRIVE AND MONITOR IMPROVEMENTS, TO UPSKILL THE WORKFORCE, TO WORK AS EQUAL PARTNERS WITH FAMILIES AND MINIMISING AND TO RESPOND APPROPRIATELY TO STRESS AND DISTRESS.

AT THE CENTRE OF THIS APPROACH IS THE INTRODUCTION OF DEMENTIA NURSE CONSULTANTS IN 13 NHS BOARDS ALONGSIDE 4 ALLIED HEALTH PROFESSIONAL CONSULTANTS. THESE NURSE CONSULTANTS ARE EXPERTS AT OPERATING AT A LEVEL OF STRATEGIC INFLUENCE WITHIN EACH NHS BOARD AND HAVE A LEAD ROLE IN TAKING FORWARD THE DEMENTIA CARE AGENDA.

THE NURSE CONSULTANTS ARE JOINED BY OVER 500 ACUTE CARE DEMENTIA CHAMPIONS WHO ARE THE OPERATIONAL CHANGE AGENTS. MOST OF THE DEMENTIA CHAMPIONS ARE NURSES AND ALLIED HEALTH WORKERS.

THERE HAS BEEN A DETAILED EVALUATION BY BLAKE STEVENSON OF THE APPROACH WHICH CONFIRMS THAT “THE MODEL IS AN APPROPRIATE AND EFFECTIVE ONE FOR IMPLEMENTING CHANGE BUT HIGHLIGHTS THAT FURTHER DEVELOPMENT IS REQUIRED IN A NUMBER OF BOARD AREAS TO MAXIMISE IMPACT AND ENSURE SUSTAINABILITY OF THE ROLES AND ALL THEY HAVE ACHIEVED TO DATE”.

I ENCOURAGE YOU TO STUDY THE EVALUATION AND CONSIDER WHAT LESSONS THIS WORK HOLDS FOR CHA

d) Quality

GOOD DEMENTIA CARE MUST HAVE A FOCUS ON QUALITY OF CARE. QUALITY IS A BROAD TERM THAT COVERS A RANGE OF ISSUES FROM ENSURING AN ADEQUATE ENVIRONMENT AND LIVING SPACES TO ACCESS TO APPROPRIATE CARE.

THERE SEEMS TO BE A RECOGNITION ACROSS THE WORLD THAT THE TIME HAS COME FOR A FUNDAMENTAL SHIFT FROM A COMPLIANCE, MINIMUM STANDARDS APPROACH TO ONE WHICH FOCUSES ON IMPROVING QUALITY AND PROVIDING INFORMATION TO CONSUMERS ABOUT QUALITY OF CARE THEY RECEIVE.

ACHIEVING THIS IS PROVING HARD IN PRACTICE.

LESS THAN A THIRD OF OECD COUNTRIES COLLECT QUALITY CARE INDICATORS SYSTEMATICALLY AND EVEN FEWER COUNTRIES MAKE THIS INFORMATION AVAILABLE OR GRADE THE PERFORMANCE OF SERVICE PROVIDERS BASED ON WEIGHTED QUALITY INDICATORS.

IN AUSTRALIA THE FOCUS ON QUALITY IN AGED CARE OVER THE LAST FEW DECADES HAS BEEN ON WEEDING OUT THE BAD APPLES AND ENSURING COMPLIANCE WITH A BASIC SET OF STANDARDS. INDEED, MORE THAN TWO-THIRDS OF OECD AND EUROPEAN COUNTRIES HAVE COMPULSORY LONG TERM

CARE ACCREDITATION OR ACCREDITATION AS A REQUIREMENT FOR REIMBURSEMENT OR CONTRACTING.

MORE AND MORE COUNTRIES ARE USING CONSUMER INVOLVEMENT IN THE EVALUATION AND ACCREDITATION OF HEALTH AND AGED CARE SERVICES TO BOTH INFORM THE PROCESS AND IMPROVE CONSUMER ENGAGEMENT.

FOR EXAMPLE IN ENGLAND CONSUMERS WORK WITH THE CARE QUALITY COMMISSION AND ARE INVOLVED IN ACCOMPANYING INSPECTORS ON VISITS TO SERVICES AND PARTICIPATING IN THE AUDITING PROCESS.

SIMILARLY, THE UNITED STATES HAVE DEVELOPED A LONG-TERM CARE OMBUDSMAN PROGRAM, WHERE ADVOCATES FOR RESIDENTS IN NURSING HOMES VISIT FACILITIES AND MONITOR CONDITIONS. THERE ARE OVER 12, 000 OMBUDSMEN VOLUNTEERS OF WHICH OVER 9, 000 ARE CERTIFIED TO INVESTIGATE COMPLAINTS.

SOME COUNTRIES, INCLUDING ENGLAND, SCOTLAND AND THE NETHERLANDS ASSESS USER EXPERIENCE THROUGH SURVEYS. CONSUMERS ARE SURVEYED ABOUT CONSUMER CHOICE, AUTONOMY, DIGNITY, COMFORT, SECURITY, RELATIONSHIPS AND SOCIAL ACTIVITY.

QUALITY INDICATORS WERE TO BE INTRODUCED TO AUSTRALIAN RESIDENTIAL CARE FACILITIES FROM 1 JULY 2014 AND COMMUNITY CARE BY JULY 2016. IT IS DOUBTFUL WHETHER THESE TIMESCALES WERE EVER REALISTIC BUT NEITHER HAS THE ISSUE BEEN GIVEN PRIORITY.

THERE ARE DEVELOPMENTS INTERNATIONALLY THAT MAY HELP THE WORK BEING DONE IN AUSTRALIA

FIRST, OECD HAVE COMMITTED TO GIVE PRIORITY TO WORK ON THE QUALITY OF DEMENTIA CARE INCLUDING THE

DEVELOPMENT OF A SMALL NUMBER OF INTERNATIONALLY COMPARABLE INDICATORS OF THE QUALITY OF DEMENTIA CARE.

SECOND, THE INTERNATIONAL CONSORTIUM FOR HEALTH OUTCOMES MEASUREMENT HAS A WORKING GROUP ON DEMENTIA. THESE GROUPS FACILITATE A PROCESS WHEREBY PHYSICIANS AND CONSUMER REPRESENTATIVES DEVELOP A GLOBAL SET OF STANDARDS THAT REALLY MATTER TO CONSUMERS. A REPORT IS DUE SHORTLY.

THIRD AUSTRALIA CAN LEARN FROM OTHER COUNTRIES SUCH AS THE UNITED STATES, SCOTLAND AND CANADA WHO ARE MUCH FURTHER DOWN THE PATH OF STANDARDS AND INDICATORS THAN AUSTRALIA.

DEMENTIA FRIENDS AND DEMENTIA FRIENDLY COMMUNITIES AND ORGANISATIONS

LASTLY, AT THE GLOBAL LEVEL THERE HAVE BEEN EXCITING DEVELOPMENTS WHICH HOLD PROMISE OF REDUCING THE STIGMA AND SOCIAL ISOLATION THAT TOO OFTEN ARE THE CONSEQUENCE OF A DIAGNOSIS OF DEMENTIA.

THE DEMENTIA FRIENDS PROGRAM WAS PIONEERED IN JAPAN IN 2005. IT IS FUNDED AND ACCREDITED BY THE JAPANESE GOVERNMENT. THERE ARE CURRENTLY 6.3 MILLION DEMENTIA FRIENDS WITH A TARGET OF 8 MILLION BY 2018.

THE PROGRAM'S *AIM* IS TO TRANSFORM PEOPLE'S PERCEPTION OF DEMENTIA BY CREATING DEMENTIA FRIENDS – PEOPLE DRAWN FROM ALL AGES, CULTURES AND LIFESTYLES – WHO LEARN ABOUT WHAT IT IS LIKE TO LIVE WITH DEMENTIA, AND THEN TURN THAT UNDERSTANDING INTO SOCIAL ACTIONS THAT LEAD TO THE DEVELOPMENT OF DEMENTIA-FRIENDLY COMMUNITIES.

THESE SOCIAL ACTIONS CAN TAKE MANY FORMS, FOR EXAMPLE, BY HELPING OUT IN A DEMENTIA CAFÉ OR BY

RAISING AWARENESS ABOUT DEMENTIA AMONG WORK COLLEAGUES, FAMILY AND FRIENDS.

110,000 JAPANESE DEMENTIA FRIENDS UNDERTOOK FURTHER TRAINING TO BECOME DEMENTIA FRIENDS CHAMPIONS. DEMENTIA FRIENDS CHAMPIONS IN TURN RECRUIT AND CREATE MORE DEMENTIA CHAMPIONS. A SORT OF PYRAMID SELLING!

THE PROGRAM IS GOING GLOBAL. BUILDING ON JAPAN'S LEAD THE ALZHEIMER'S SOCIETY IN THE UK HAS BEEN PARTICULARLY ACTIVE SINCE 2013 AS PART OF THE CHALLENGE ON DEMENTIA LED BY THE PRIME MINISTER DAVID CAMERON. A CODE OF PRACTICE FOR THE RECOGNITION OF DEMENTIA FRIENDLY COMMUNITIES HAS BEEN DEVELOPED BY THE BRITISH STANDARDS AUTHORITY PAS 1365:2015

OTHER COUNTRIES HAVE BEEN INSPIRED TO FOLLOW SUIT AND I HOPE THAT AUSTRALIA DOES TOO AND BUILDS ON THE FEW GREEN SHOOTS THAT CURRENTLY EXIST.

CONCLUSION

I HAVE BEEN CHAIR OF ADI FOR LESS THAN FOUR MONTHS BUT ALREADY I FEEL THAT AUSTRALIA HAS MUCH TO LEARN FROM OVERSEAS.

THE PRIORITY GIVEN TO DEMENTIA RESEARCH BY THE CURRENT GOVERNMENT IS A BIG ACHIEVEMENT AS IS THE INTRODUCTION OF CONSUMER DIRECTED CARE AND EXPANDED COMMUNITY CARE. BUT THE IMPLEMENTATION OF THE 2012 REFORMS HAS NOT MEASURED UP TO THE PROMISE. THERE IS A NEED TO TAKE ACTION ON:

- TIMELY DIAGNOSIS AND POST DIAGNOSTIC SUPPORT INCLUDING BY THE CONTINUED FUNDING OF DEMENTIA KEY WORKERS;
- EXPANDING ACCESS TO FLEXIBLE DEMENTIA RESPITE;
- IMPROVING THE QUALITY OF LONG TERM RESIDENTIAL DEMENTIA CARE THROUGH A DEMENTIA SUPPLEMENT
- ENHANCING THE QUALITY OF DEMENTIA CARE IN ACUTE CARE

- PROJECTS TO SUPPORT DEMENTIA FRIENDLY CHAMPIONS AND COMMUNITIES.
- QUALITY INDICATORS AND CAPTURING RESIDENTS EXPERIENCE
- DEMENTIA RISK REDUCTION

THAT WOULD BE A GREAT BASIS FOR TACKLING DEMENTIA BY GOVERNMENT AND ORGANISATIONS SUCH AS CHA.

WITH THE FOCUS ON GATEWAYS AND TECHNOLOGY WE RISK LOSING THE HUMAN FACE AND RECOGNITION OF THE NEED FOR SPECIALIST SKILLS IN THE COMMUNITY TO SUPPORT AND CARE FOR SPECIAL GROUPS INCLUDING THOSE WITH DEMENTIA. THAT IS WHY DEMENTIA FRIENDLY COMMUNITIES, DEMENTIA KEY WORKERS AND RESPITE MATTER.

MUCH AS ALL OF US AND GOVERNMENTS WOULD WISH IT THERE IS 'NO ONE SIZE FITS ALL APPROACH WITH DEMENTIA'. THE DESTINATION IS INEVITABLE BUT EVERY PERSON'S DEMENTIA JOURNEY IS UNIQUE TO THEM.

MY THANKS TO ALZHEIMER'S SCOTLAND AND DR MAYUMI HAYASHI FOR THEIR HELP IN PROVIDING INFORMATION FOR THIS TALK