

25<sup>TH</sup> ANNIVERSARY CELEBRATION

ALZHEIMER'S DISEASE ASSOCIATION OF SINGAPORE

DEMENTIA FRIENDLY COMMUNITIES: GLOBAL INITIATIVES AND FUTURE  
DIRECTIONS

GLENN REES AM

CHAIR, ALZHEIMER'S DISEASE INTERNATIONAL

MR GAN KIM YONG, MINISTER FOR HEALTH, DR NG LI LING, CHAIRPERSON, ORGANISING COMMITTEE OF 'TOWARDS A DEMENTIA FRIENDLY SINGAPORE SYMPOSIUM', DR ANG PENG CHYE, PRESIDENT, ALZHEIMER'S DISEASE ASSOCIATION, DISTINGUISHED GUESTS, LADIES AND GENTLEMEN

I WOULD LIKE TO CONGRATULATE THE ALZHEIMER'S DISEASE ASSOCIATION OF SINGAPORE FOR TAKING THE INITIATIVE TO ORGANIZE THIS SYMPOSIUM AND ACKNOWLEDGE OUR APPRECIATION TO THE NATIONAL COUNCIL OF SOCIAL SERVICE AND THE AGENCY FOR INTEGRATED CARE FOR THEIR SUPPORT AND COLLABORATION IN PROMOTING A DEMENTIA FRIENDLY SINGAPORE. THE ALZHEIMER'S DISEASE INTERNATIONAL IS HAPPY TO SHARE AND LEND ITS EXPERIENCES FROM AMONGST ITS MEMBER ASSOCIATIONS.

THANK YOU FOR THE OPPORTUNITY TO CELEBRATE WITH YOU THIS IMPORTANT MILESTONE IN THE LIFE OF ALZHEIMER'S DISEASE ASSOCIATION OF SINGAPORE.

I HAVE THE HIGHEST REGARD FOR ADA NOT ONLY BECAUSE OF THE GOOD WORK IT DOES IN SINGAPORE BUT ALSO BECAUSE OF ITS GENEROSITY IN SUPPORTING ORGANISATIONS LESS WELL POSITIONED IN THE ASIA PACIFIC REGION

I HAVE BEEN ASKED TO TALK ABOUT DEMENTIA FRIENDLY COMMUNITIES AND TO RESPOND TO THE OUTCOME OF THE FOCUS GROUPS HELD EARLIER THIS YEAR.

IN MY EXPERIENCE ONE OF THE POSITIVES OF AGEING – AND I KNOW I LOOK TOO YOUNG TO TALK LIKE THAT – IS THE OPPORTUNITY TO REFLECT. THE IDEA OF DEMENTIA FRIENDLY COULD NOT SERIOUSLY HAVE BEEN CONTEMPLATED THIRTY YEARS AGO.

AT THAT TIME IN 1985 I CHAIRED A REVIEW OF AGED CARE IN AUSTRALIA WHICH HAD AS ITS MAIN PURPOSE REBALANCING THE AGED CARE SYSTEM AWAY FROM AN EXCESSIVE RELIANCE ON INSTITUTIONAL CARE TO COMMUNITY BASED APPROACHES. BACK THEN, POLICY MAKERS HAD A VERY LIMITED UNDERSTANDING OF DEMENTIA OR WHAT TO DO ABOUT IT.

IN THE INTERVENING PERIOD SINCE THEN I THINK WE CAN BE PLEASED WITH THE INCREASED GLOBAL RECOGNITION OF DEMENTIA. TWENTY COUNTRIES NOW HAVE PLANS AND ADI ANTICIPATES THIS WILL INCREASE TO TWENTY FIVE BY THE END OF THIS YEAR.

PLANS DON'T ALWAYS MEAN ACTION THOUGH AND ADI IS VERY CONSCIOUS THAT MANY LOW AND MIDDLE INCOME COUNTRIES HAVE LOW

AWARENESS OF DEMENTIA, AND HEALTH AND CARE SYSTEMS THAT ARE NOT POSITIONED TO ADDRESS THE ISSUE.

SO I HAVE NO REASON TO CHANGE MY VIEW THAT REVOLUTION RATHER THAN EVOLUTION IS NECESSARY TO ACHIEVE THE ACTION WE NEED TO TACKLE DEMENTIA.

THE FIRST VICTORY IN ANY REVOLUTION IS TO PERSUADE OTHERS TO USE YOUR INFORMATION AND LANGUAGE.

THE RECENT 2015 WORLD ALZHEIMER'S REPORT FOUND THAT THERE HAS BEEN A 12-13 % INCREASE IN THE GLOBAL ESTIMATES OF PEOPLE WITH DEMENTIA SINCE THE 2009 REPORT – MUCH OF THE INCREASE HAS OCCURRED IN LOW AND MIDDLE INCOME COUNTRIES. THE NUMBERS ARE EXTRAORDINARY

- 46.8 MILLION PEOPLE WORLD WIDE NOW LIVE WITH DEMENTIA. THIS NUMBER WILL GROW TO 131.5 MILLION BY 2050
- THERE WILL 9.9 MILLION NEW CASES OF DEMENTIA BY THE END OF THIS YEAR
- THE TOTAL ESTIMATED COST OF DEMENTIA IS US \$813 BILLION, A FIGURE PROJECTED TO INCREASE BY 2018 TO US \$1 TRILLION.

HAVING RAISED THE AWARENESS OF GOVERNMENTS OF THE IMMENSITY OF THE ISSUE OF DEMENTIA IT IS INCREASINGLY THE LANGUAGE AND ATTITUDES WE ADOPT THAT MATTER IN ACHIEVING CHANGE.

AND THAT IS WHERE THE LANGUAGE OF DEMENTIA FRIENDLY COMES INTO PLAY. THE CONCEPT OF DEMENTIA FRIENDLY POTENTIALLY TOUCHES EVERY ASPECT OF DAILY LIFE AND THE PROVISION OF SERVICES

AFTER EXPLORING WHAT THE CONCEPT MEANS I WILL SPELL OUT WHAT IT MIGHT MEAN IN TERMS OF PRACTICAL ACTION

## **THE CONCEPT**

THE CONCEPT OF DEMENTIA FRIENDLY HAS CAPTURED THE IMAGINATION OF CONSUMERS, POLICY MAKERS AND RESEARCHERS AROUND THE WORLD. IT HAS BEEN IMPLEMENTED IN A RANGE OF DIFFERENT AND INNOVATIVE WAYS AS RECENTLY DESCRIBED IN THE ALZHEIMER'S DISEASE INTERNATIONAL PUBLICATION ON DEMENTIA FRIENDLY-COMMUNITIES.

AT ONE LEVEL THE CONCEPT OF DEMENTIA FRIENDLY IS BEGUILINGLY SIMPLE... NAMELY, TO WORK FOR THE COMMON GOAL OF A BETTER LIFE FOR PEOPLE WITH DEMENTIA. BUT IT IS MUCH MORE THAN THIS.

DEMENTIA FRIENDLY COMMUNITIES HAS THE POWER TO CHANGE THE WAY WE THINK ABOUT LIVING WITH DEMENTIA.

IT MARKS A FUNDAMENTAL SHIFT FROM A FOCUS ON MEETING THE PHYSICAL AND HEALTH NEEDS OF THE PERSON WITH DEMENTIA TO A HOLISTIC APPROACH TO SUPPORTING THE PERSON TO ACHIEVE THE BEST QUALITY OF LIFE REASONABLY POSSIBLE. IT SEEMS SO SIMPLE, YET IT HAS TAKEN ALMOST TEN YEARS SINCE JAPAN INITIATED DEMENTIA FRIENDS FOR THE IDEA TO DEVELOP ITS OWN DYNAMIC.

THERE IS A RISK THAT AS THE APPROACHES TO DEMENTIA-FRIENDLY COMMUNITIES PROPAGATE, THERE IS A FOCUS ON THE MEANS OF ACHIEVING DEMENTIA FRIENDLY COMMUNITIES AND NOT ENOUGH ON WHAT WE ARE TRYING TO ACHIEVE.

IT SEEMS TO ME THAT THERE IS A WORLD OF DIFFERENCE BETWEEN TWO VERY DIFFERENT UNDERLYING OBJECTIVES OF DEMENTIA FRIENDLY COMMUNITIES WHICH HAVE AS THEIR END GOAL A BETTER LIFE FOR PEOPLE WITH DEMENTIA.

FIRST, THE OBJECTIVE OF REDUCING STIGMA AND UNDERSTANDING OF DEMENTIA BY GREATER AWARENESS AND MEANINGFUL ENGAGEMENT FOR PERSONS WITH DEMENTIA OF ALL AGES...THAT IS THE LIVED EXPERIENCE APPROACH

SECOND, THE OBJECTIVE OF EMPOWERING PEOPLE WITH DEMENTIA BY RECOGNISING THEIR RIGHTS AND CAPABILITIES SO THAT THEY FEEL RESPECTED, AND TO THE EXTENT THAT THEY ARE ABLE, EMPOWERED TO TAKE DECISIONS ABOUT THEIR LIVES. THIS APPROACH BELIEVES THAT THE DEMENTIA CHALLENGE IS TO CREATE A SOCIETY WHERE DEMENTIA IS NORMALISED AND ACCEPTED AS A DISABILITY.

I DETECT THAT THE CONCEPT OF DEMENTIA FRIENDLY COMMUNITIES IS BEING GIVEN PRACTICAL EXPRESSION IN AT LEAST FOUR DIFFERENT WAYS.

1. **HUMAN RIGHTS.** FOR THE FIRST TIME, POLICY MAKERS AND CONSUMERS ARE FOCUSING ON SUPPORTING AND PROTECTING THE RIGHTS OF A PERSON WITH DEMENTIA IN A SIMILAR WAY TO WHAT HAS BEEN ACHIEVED IN THE DISABILITY FIELD. FOR EXAMPLE THE CHARTER OF RIGHTS OF PEOPLE WITH DEMENTIA AND THEIR CARERS IN SCOTLAND AND RECENT WORK TO ENSURE THAT DEMENTIA IS INCLUDED IN THE CONVENTION ON THE RIGHTS OF PERSONS WITH DISABILITIES.

2. **PUBLIC AWARENESS.** SOME COUNTRIES ARE FOCUSING ON TACKLING THE STIGMA AND LACK OF COMMUNITY UNDERSTANDING OF DEMENTIA. THIS APPROACH IS EXEMPLIFIED BY THE DEMENTIA FRIENDS AND DEMENTIA FRIENDLY COMMUNITIES IN JAPAN AND THE UNITED KINGDOM. POTENTIALLY THIS TOUCHES ON EVERY ASPECT OF DAILY LIFE.
3. **HEALTH AND SERVICES.** THE DEMENTIA-FRIENDLY FOCUS ON HEALTH AND SERVICES IS ABOUT INCREASING CAPABILITY OF WORKFORCE AND AVAILABILITY OF KEY SERVICES AND DEVELOPING INNOVATIVE AND APPROACHES TO SERVICES THAT ADDRESS SOCIAL AS WELL AS PHYSICAL NEEDS. FOR EXAMPLE THE US NATIONAL DEMENTIA PLAN AND THE AUSTRALIAN EMPHASIS ON FUNDING NEW PROGRAMS AND RESEARCH
4. **PHYSICAL ENVIRONMENT.** WHETHER IN RESIDENTIAL FACILITIES, PUBLIC SPACES OR GOVERNMENT BUILDINGS, IN SOME COMMUNITIES SMALL STEPS ARE BEING TAKEN TO IMPROVE THE PHYSICAL ENVIRONMENT – A TOPIC THAT IS CENTRAL TO THE AGEING CITIES MOVEMENT AND ONE WHICH RICHARD WILL DEAL WITH LATER TODAY

THESE APPROACHES ARE NOT EXCLUSIVE – INDEED I WOULD SAY THAT TO VARYING DEGREES, ALZHEIMER’S SCOTLAND HAS EMBRACED ALL FOUR ALTHOUGH DRIVEN BY THE PRINCIPLES UNDERLYING A HUMAN RIGHTS APPROACH.

SIMILARLY, SINGAPORE’S AMBITIOUS ACTION PLAN FOR SUCCESSFUL AGEING EMBRACES THREE ELEMENTS DIRECTED AT LIVING WELL, BUILDING A COHESIVE SOCIETY WITH INTERGENERATIONAL HARMONY AND BUILDING AN AGE FRIENDLY CITY. AS A CONSEQUENCE SINGAPORE MAY BE WELL PLACED TO ADOPT DEMENTIA FRIENDLY PRIORITIES FOR EXAMPLE IN EDUCATION, ACTIVE AGEING, OPPORTUNITIES FOR VOLUNTEERING, MAXIMISING INTER-GENERATIONAL INTERACTION AND TRANSPORT.

THE COMPLEXITY AND DIVERSITY OF VIEWS ABOUT WHAT DEMENTIA FRIENDLY MEANS IS WHY SINGAPORE AS A FIRST STEP HAS BEEN RIGHT TO SEEK THE VIEWS OF FOCUS GROUPS. THEY HAVE PROVIDED A WEALTH OF INFORMATION. OVERALL IT SEEMS THAT ACROSS THE RANGE OF GROUPS THERE IS AN OVERWHELMING VIEW THAT SINGAPORE IS NOT DEMENTIA FRIENDLY OR ONLY FAIRLY DEMENTIA FRIENDLY. I SUSPECT THAT OUTCOME WOULD NOT BE SO DIFFERENT GLOBALLY WHICH IS WHY THE CONCEPT IS IMPORTANT

AMONG THE TOP THREE RESPONSES OF WHAT DEMENTIA FRIENDLY MEANS TO YOU IS PUBLIC AWARENESS AND UNDERSTANDING OF DEMENTIA, A SUPPORTIVE AND EMPATHETIC SOCIETY AND AN INCLUSIVE SOCIETY.

IT FOLLOWS THAT THE MOST IMPORTANT CHALLENGE IS IDENTIFIED BY THE GROUPS AS LACK OF AWARENESS AND STIGMA BUT ALSO RANKED HIGHLY ARE LACK OF DAY CENTRES AND RED TAPE IN GOVERNMENT SUPPORT.

WHEN IT COMES TO ADDRESSING THE ISSUES AND CHALLENGES INCREASING AWARENESS IS WAY OUT AHEAD WITH SUPPORT TOO FOR THE MINISTRY OF EDUCATION TO INCLUDE DEMENTIA IN THE SYLLABUS IN SCHOOLS AND CLOSER COLLABORATION BETWEEN COMMUNITY PARTNERS.

AT THE RISK OF OVER SIMPLIFICATION THE RESPONSES SUGGEST TO ME A PRIORITY IN SINGAPORE FOR IMPROVING THE LIVED EXPERIENCE OF DEMENTIA THROUGH COMMUNITY BASED APPROACHES AND ACCESS TO DEMENTIA FRIENDLY SERVICES RATHER THAN A RIGHTS BASED APPROACH.

IT IS IMPORTANT TO SAY WHAT DEMENTIA FRIENDLY IS NOT

- IT IS NOT THE SAME AS CHARITY – IT IS NOT A GIFT BUT A RIGHT TO PARTICIPATE IN SOCIETY
- IT IS NOT SIMPLY ABOUT NUMBERS OF DEMENTIA FRIENDS
- OR ABOUT ACHIEVING LIGHT TRAINING OF DEMENTIA FRIENDS IF THAT DOESN'T LEAD TO DEMENTIA FRIENDLY COMMUNITIES
- AND IT IS NOT ABOUT RELIEVING GOVERNMENT OF THEIR RESPONSIBILITIES

I AM NOT TRYING TO PLAY WORD GAMES OF THE KIND WE HAVE HAD ABOUT ISSUES LIKE PERSON CENTRED CARE. TO THE CONTRARY I AM INCLINED TO BE SUPPORTIVE OF ANY OF THE FOUR APPROACHES, PROVIDED THERE IS TRANSPARENCY ABOUT WHAT OUTCOMES ARE SOUGHT... SUBJECT TO ONE CAVEAT...

DEMENTIA FRIENDLY HAS TO INVOLVE PEOPLE WITH DEMENTIA AS EQUAL PARTNERS. THAT IS NON NEGOTIABLE

DEVELOPING LOCAL DEMENTIA ALLIANCES, SUCH AS WAS DONE IN KIAMA IN AUSTRALIA, IS ONE SUCCESSFUL WAY OF ENSURING THAT LOCAL PEOPLE WITH DEMENTIA ARE PARTNERS IN CREATING DEMENTIA-FRIENDLY COMMUNITIES.

TO ACHIEVE DEMENTIA FRIENDLY SOCIETIES WILL REQUIRE\_A CHANGE IN ATTITUDES AND CULTURE OF THE KIND THAT PEOPLE WITH DISABILITIES AND THEIR ADVOCATES HAVE FOUGHT FOR OVER MANY DECADES AND ARE FOUNDED IN THE CONVENTION ON THE RIGHTS OF PEOPLE WITH DISABILITIES.

MANY OF THE CONCERNS AND FRUSTRATIONS THAT PEOPLE WITH DEMENTIA EXPRESS ABOUT THE CONSEQUENCES OF THEIR DIAGNOSIS ON THEIR DAILY LIVES ARE ADDRESSED IN THE WIDE –RANGING PROVISIONS OF THE CONVENTION ON THE RIGHTS OF PEOPLE WITH DISABILITIES. FOR EXAMPLE:

- ARTICLE 2 ON EQUAL RECOGNITION BEFORE THE LAW AND SUPPORTED DECISION MAKING THAT RESPECTS THE PERSON'S CAPACITY
- ARTICLE 19 ON LIVING INDEPENDENTLY AND BEING INCLUDED IN THE COMMUNITY AND,
- ARTICLES 24, 27, 28 AND 30 WHICH INCLUDE COMPREHENSIVE ACCESS TO SERVICES INCLUDING EDUCATION, WORK, PARTICIPATION IN RECREATIONAL AND SPORTING ACTIVITIES

THE BOARD OF ADI HAS ASKED THE CEO TO APPROACH ALZHEIMER'S SCOTLAND WITH A VIEW TO SETTING UP A WORKING GROUP WITH PEOPLE WITH DEMENTIA ON DEMENTIA AND HUMAN RIGHTS. THE AIM IS TO DEVELOP A STRATEGY ON THE RECOGNITION OF DEMENTIA WITHIN THE CONVENTION.

THE CONCLUSION SEEMS TO BE THAT WE SHOULD NOT ONLY WORK HARD TO PROMOTE THE LIVED EXPERIENCE OF PEOPLE WITH DEMENTIA THROUGH DEMENTIA FRIENDLY COMMUNITIES BUT ALSO TO SEEK THE INCLUSION OF DEMENTIA WITHIN THE CONVENTION ON THE RIGHTS OF PEOPLE WITH DISABILITIES.

### **PRACTICAL ACTION**

SO WHAT ARE THE IMPORTANT WAYS IN WHICH WE CAN GIVE PRACTICAL EXPRESSION TO THE CONCEPT OF DEMENTIA FRIENDLY. TODAY I WANT TO FOCUS ON:

- A) COMMUNITIES, ORGANISATIONS AND GOVERNMENTS
- B) NEW DEMENTIA FRIENDLY MODELS OF CARE
- C) MAKING THE HEALTH SYSTEM DEMENTIA FRIENDLY
- D) PROVIDING DEMENTIA FRIENDLY INFORMATION

## **A) SO FIRST COMMUNITIES, ORGANISATIONS AND GOVERNMENTS**

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 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.

DEMENTIA FRIENDS IN TURN RECRUIT AND CREATE MORE DEMENTIA FRIENDS. A SORT OF PYRAMID SELLING CONCEPT!

THE PROGRAM IS NOW 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 PRIME MINISTER DAVID CAMERON. A CODE OF PRACTICE FOR THE RECOGNITION OF DEMENTIA FRIENDLY COMMUNITIES HAS BEEN DEVELOPED BY THE BRITISH STANDARDS AUTHORITY.

A PARTICULARLY INTERESTING DEVELOPMENT IS THE FORMATION IN THE UK OF A DEMENTIA ACTION ALLIANCE OF 1400 ORGANISATIONS ACROSS ENGLAND COMMITTED TO TRANSFORMING THE LIVES OF PEOPLE WITH DEMENTIA AND THEIR CARERS. THE ALLIANCE HAS ONE SIMPLE AIM: TO BRING ABOUT A SOCIETY-WIDE RESPONSE TO DEMENTIA. IT ENCOURAGES AND SUPPORTS COMMUNITIES AND ORGANISATIONS ACROSS ENGLAND TO TAKE PRACTICAL ACTIONS TO ENABLE PEOPLE TO LIVE WELL WITH DEMENTIA AND REDUCE THE RISK OF COSTLY CRISIS INTERVENTION.

THERE ARE 180 LOCAL DEMENTIA ACTION ALLIANCES THAT BRING TOGETHER REGIONAL AND LOCAL MEMBERS TO PROVIDE A LOCAL VEHICLE TO DEVELOP DEMENTIA FRIENDLY COMMUNITIES.

OTHER COUNTRIES HAVE BEEN INSPIRED TO FOLLOW SUIT IN DEVELOPING DEMENTIA FRIENDLY COMMUNITIES IN THEIR OWN WAY.



BUSINESS ORGANISATIONS INCLUDING BANKS HAVE RECOGNISED IT IS IN THEIR BUSINESS INTERESTS TO TRAIN STAFF AND MAKE THEIR SERVICE MORE DEMENTIA FRIENDLY.

THERE ARE EXCELLENT RESOURCES TO HELP ALZHEIMER'S ORGANISATIONS DEVELOP THEIR OWN APPROACHES ON THE WEBSITES OF THE UK SOCIETY AND ALZHEIMER'S AUSTRALIA. OVER THE NEXT 12 MONTHS ADI WILL DEVELOP A SET OF LINKS TO THIS MATERIAL AND ENABLE MEMBERS TO POST PROJECTS THEY ARE ENGAGED IN.

ALZHEIMER'S ORGANISATIONS HAVE A RESPONSIBILITY TO BE DEMENTIA FRIENDLY BY BEING INCLUSIVE OF PEOPLE WITH DEMENTIA BY ACTIVELY INVOLVING THEM IN ADVOCACY, SPEAKING AT EVENTS AND IN THE DEVELOPMENT OF POLICY POSITIONS.

ALL ALZHEIMER'S ORGANISATIONS – IF THEY HAVEN'T ALREADY – SHOULD PUT IN PLACE AN ADVISORY GROUP OF PEOPLE WITH DEMENTIA WHEN THE RESOURCES PERMIT AND OPPORTUNITY ARISES.

IT GAVE ME GREAT PLEASURE DURING THE LAST HALF OF 2014 TO ADVOCATE FOR ADI TO ENTER A PARTNERSHIP WITH THE DEMENTIA ALLIANCE INTERNATIONAL (DAI) RATHER THAN ESTABLISH AN ADI GROUP.

I HAVE BEEN AROUND LONG ENOUGH NOW TO KNOW THAT, HOWEVER WELL-INTENTIONED, GROUPS THAT ARE SET UP WITHIN ORGANISATIONS ARE SUBJECT TO CONTROL WHICH OVER TIME LEAD TO FRUSTRATION AND TENSION

EQUALLY IT IS IMPORTANT THAT DAI NOT ONLY HAS POSITIONS OF ITS OWN BUT THAT ADI TOO HAS THE CAPACITY TO PURSUE ISSUES IN THE WAY IT THINKS BEST, FOR EXAMPLE IN RESPECT OF THE BUSINESS MODEL FOR CONFERENCES OR THE MOST EFFECTIVE WAY TO PROSECUTE GLOBAL ADVOCACY.

PARTNERSHIP BASED ON MUTUAL RESPECT IS THE BEST WAY FORWARD. A START HAS BEEN MADE. DAI HAS DETERMINED PROJECTS WHICH ARE A PRIORITY FOR SUPPORT BY ADI AND ESTABLISHED A BASIS TO DEVELOP CONFERENCES RUN BY PEOPLE WITH DEMENTIA, STARTING WITH THE REGIONAL CONFERENCE IN NEW ZEALAND NEXT YEAR

GOVERNMENTS HAVE THEIR RESPONSIBILITIES TOO. EXPERIENCE AROUND THE WORLD SUGGESTS THAT POLITICAL SUPPORT AND SOME INJECTION OF FUNDING IS NECESSARY FOR SUCCESS.

HAVING PROJECT OFFICERS FUNDED TO GET ACTION HAPPENING ON THE GROUND IS CRITICAL AS IS THE NEED FOR BASIC RESOURCES TO CREATE

WEBSITES, TRAINING AND RESOURCE KITS FOR COMMUNITIES AND ORGANISATIONS. MAKING USE OF THE MANY RESOURCES THAT ALREADY EXIST GLOBALLY IS ALSO IMPORTANT.

AND MANY RESOURCES NOW EXIST AROUND THE WORLD TO DRAW ON.

AS ALWAYS IT IS NOT EASY TO GET A GOOD HANDLE ON WHAT HAS BEEN SPENT BY GOVERNMENTS AND ORGANISATIONS BUT THE AMOUNTS ARE NOT LARGE IN THE CONTEXT OF THE ECONOMIC AND SOCIAL COSTS OF DEMENTIA – I SUSPECT US \$10 MILLION OVER THREE OR FOUR YEARS WOULD GO A LONG WAY TO GETTING THE ACTION THAT IS REQUIRED.

## **B) NEW MODELS OF CARE**

THERE ARE MANY WAYS IN WHICH THE SERVICES COULD BE MADE MORE DEMENTIA FRIENDLY TO ENABLE PEOPLE WITH DEMENTIA TO LIVE AS LONG AS POSSIBLE IN THE COMMUNITY.

THERE NEEDS TO BE A SERIOUS DISCUSSION ABOUT CASH VERSUS SERVICE MODELS OF SUPPORTING PEOPLE WITH DEMENTIA AND THEIR FAMILIES.

IF WE BELIEVE IN BEING DEMENTIA FRIENDLY AND HAVING FLEXIBILITY IN SERVICE DELIVERY, AND IN USING MARKET FORCES WHERE WE CAN THEN ARGUABLY CONSUMERS SHOULD HAVE THE OPTION OF CASH RATHER THAN GOVERNMENT FUNDED SERVICES.

THERE IS PERHAPS NO SERVICE THAT REQUIRES MORE FLEXIBILITY IN TERMS OF LOCATION, TIMING AND SUPPORT THAN RESPITE. IF CONSUMERS ARE TO HAVE CHOICE AND ACCESS TO DEMENTIA FRIENDLY RESPITE THEY NEED TO HOLD THE CASH AND DETERMINE WHAT WOULD BEST MEET THEIR NEEDS.

IT IS ALL TOO OFTEN THE CASE IN AUSTRALIA THAT THERE IS LACK OF FLEXIBILITY IN ACCESS TO RESPITE WITH SERVICES NOT POSITIONED TO SUPPORT THOSE AT THE MODERATE OR MORE ADVANCED STAGES OF DEMENTIA. THERE IS A GREAT DISPARITY TOO BETWEEN SERVICES IN THEIR CAPACITY TO SUPPORT ACTIVITIES AND REHABILITATIVE APPROACHES.

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. A STRATEGY INCLUDED IN SINGAPORE'S ACTION PLAN FOR SUCCESSFUL AGEING.

LASTLY I WANT TO POSE A QUESTION FOR YOU TO CONSIDER. WHETHER WE CAN MAKE RESIDENTIAL CARE DEMENTIA FRIENDLY. AND IF YOU AGREE WITH THIS LINE OF THOUGHT HOW DO WE GO ABOUT IT?

THERE ARE MANY WAYS I THINK AND SOME RESIDENTIAL CARE PROVIDERS IN AUSTRALIA HAVE ADOPTED THEM. THEY INCLUDE:

- A LEADERSHIP COMMITTED TO A PERSON CENTRED PHILOSOPHY

- STRATEGIES TO REDUCE PHYSICAL AND MEDICAL RESTRAINT
- STAFF WHO VALUE THE RESIDENTS AND FAMILY CARERS AND COMMUNICATE WITH THEM
- FLEXIBILITY IN THE TIMING OF SHOWERS AND MEALS,
- ACCESS TO ALLIED HEALTH SERVICES
- AN ACTIVITIES PROGRAM
- MONITORING OUTCOMES AND RESIDENT'S EXPERIENCE

OF THESE, THE ISSUE THAT HAS CONCERNED ME MOST OVER MANY YEARS AS A SIGN OF POOR CARE IN THE AUSTRALIAN CONTEXT IS THE EXCESSIVE USE OF ANTI-PSYCHOTIC MEDICATIONS BY SOME RESIDENTIAL CARE SERVICES. WE KNOW THESE DRUGS HAVE SEVERE SIDE EFFECTS INCLUDING DEATH AND SHOULD BE USED AS A LAST RESORT AFTER PSYCHO-SOCIAL APPROACHES HAVE BEEN TRIED.

YET AVAILABLE EVIDENCE SUGGESTS THAT UPTO 80 PER CENT OF RESIDENTS IN SOME HOMES WITH DEMENTIA ARE ON THESE MEDICATIONS. PERHAPS 20 PER CENT GAIN SOME BENEFIT. HARDLY DEMENTIA FRIENDLY.

### **C) MAKING THE HEALTH SYSTEM DEMENTIA FRIENDLY SHOULD BE A PRIORITY**

AND IF THE HEALTH SYSTEM IS TO BE MORE DEMENTIA FRIENDLY THE INITIAL PRIORITY IS TIMELY DIAGNOSIS AND ACUTE CARE

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 35 MILLION PEOPLE LIVING WITH DEMENTIA DO NOT HAVE ACCESS TO INFORMATION, CARE AND TREATMENT.

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 CER 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 THE 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.

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

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.

FOR MANY YEARS NOW AUSTRALIAN CONSUMERS HAVE 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.

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 COUNTRIES THAT HAS PRIORITISED IMPROVING DEMENTIA CARE IN HOSPITALS, INCLUDING DEVELOPING AND IMPROVING ALTERNATIVES TO HOSPITAL ADMISSION.

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 RESPONDING APPROPRIATELY TO STRESS AND DISTRESS.

AT THE CENTRE OF THIS APPROACH IS THE INTRODUCTION OF DEMENTIA NURSE CONSULTANTS IN 13 NATIONAL HEALTH SERVICE 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 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".

#### **D) DEMENTIA FRIENDLY INFORMATION**

AN IMPORTANT WORD IN AGED CARE POLICY IN AUSTRALIA FOR OVER THIRTY YEARS HAS BEEN CHOICE. THE CHOICE BETWEEN HOME CARE AND RESIDENTIAL CARE TO HAVE THE OPTION OF STAYING AT HOME FOR AS LONG AS POSSIBLE. AND AS A CONSEQUENCE OF THE 2012 AGED CARE REFORMS A NEW DIMENSION OF CHOICE THROUGH CONSUMER DIRECTED CARE - NAMELY TO GIVE THE CONSUMER THE CHOICE OF SERVICES AND

WHERE AND WHEN THEY ARE DELIVERED AND BY WHICH SERVICE PROVIDER.

THIS NEW APPROACH OF CONSUMER DIRECTED CARE TO EMPOWER THE CONSUMER TO TAKE DECISIONS EVIDENTLY IS PRE-CONDITIONED NOT ONLY BY A CHANGE OF CULTURE ON THE PART OF CONSUMERS AND SERVICE PROVIDERS BUT ALSO BY THE AVAILABILITY OF GOOD INFORMATION.

MORE RECENTLY IN AUSTRALIA THERE HAS BEEN A SIGNIFICANT INVESTMENT IN NEW INFORMATION GATEWAYS TO CAPTURE SERVICE INFORMATION BUT WHAT IS STILL LACKING IS TRANSPARENCY IN THE OUTCOMES BEING ACHIEVED OR THE VIEWS OF OLDER PEOPLE AND THEIR FAMILIES ON THE SERVICES THEY RECEIVE

AUSTRALIA IT SEEMS IS NOT ALONE IN STRUGGLING WITH THIS ISSUE. 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 THE 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 IN RESIDENTIAL CARE 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.

THERE ARE SIGNS OF CHANGE.

SOME 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.

AUSTRALIA IS NOW PILOTING THREE OUTCOME INDICATORS IN RESIDENTIAL CARE – NAMELY PRESSURE INJURIES, WEIGHT LOSS AND PHYSICAL RESTRAINT. CONSIDERATION IS ALSO BEING GIVEN TO THE POTENTIAL OF REPORTING TO CAPTURE RESIDENT'S EXPERIENCE AND QUALITY OF LIFE.

## **CONCLUSION**

IT IS EARLY DAYS IN REALISING THE FULL POTENTIAL OF DEMENTIA FRIENDLY COMMUNITIES.

THE STRENGTH AND THE WEAKNESS OF THE CONCEPT IS THAT IT CAN MEAN SO MANY DIFFERENT THINGS. BUT THE NON NEGOTIABLE OUTCOME IS THAT IT MUST ENSURE THAT PEOPLE WITH DEMENTIA ARE EQUAL PARTNERS IN COMMUNITY LIFE AND IN ALZHEIMER'S ASSOCIATIONS, AND MOST IMPORTANTLY POSITION THEM TO TAKE DECISIONS OVER THEIR OWN LIVES TO THE EXTENT THEY ARE ABLE.

I BELIEVE WE KNOW ENOUGH TO TAKE ACTION ON MAKING OUR COMMUNITIES DEMENTIA FRIENDLY. WHETHER BY ESTABLISHING SIGNIFICANT NUMBERS OF DEMENTIA FRIENDS, CAFES AND ACTIVITIES, DEMENTIA FRIENDLY BUSINESSES AND WORKPLACES OR DEMENTIA FRIENDLY LONG TERM CARE AND HEALTH SYSTEMS.

I SUGGEST THAT IN SEEKING PRACTICAL WAYS TO IMPROVE THE QUALITY OF THE LIVES OF PEOPLE WITH DEMENTIA WE SHOULD BE SETTING OURSELVES TWO OBJECTIVES.

FIRST TO PROMOTE THE LIVED EXPERIENCE OF PEOPLE WITH DEMENTIA THROUGH DEMENTIA FRIENDLY COMMUNITIES. SECOND TO SEEK INCLUSION OF DEMENTIA WITHIN THE CONVENTION ON THE RIGHTS OF



PEOPLE WITH DISABILITIES TO SECURE EQUAL RECOGNITION BEFORE THE LAW, LIVING INDEPENDENTLY AND BEING INCLUDED IN THE COMMUNITY.

OF COURSE IT IS NOT ENOUGH FOR IT TO BE STATED ON PAPER. IT MUST LEAD TO A REAL CHANGE IN HOW WE SUPPORT PEOPLE WITH DEMENTIA. TO ACHIEVE THESE GOALS WILL REQUIRE FUNDING AND SUPPORT FROM ALL LEVELS OF GOVERNMENT AS WELL AS BUSINESS AND THE WIDER COMMUNITY.

I WISH SINGAPORE EVERY SUCCESS IN PLANNING NATIONALLY FOR DEMENTIA AND IN IMPLEMENTING DEMENTIA FRIENDLY COMMUNITIES.

THANK YOU