

**LEADERSHIP IN QUALITY DEMENTIA CARE FORUM**

**ALZHEIMER'S AUSTRALIA VICTORIA LEADERSHIP FORUM &  
LAUNCH OF MONTESSORI ACTIVITIES RESOURCES  
MELBOURNE CONVENTION AND EXHIBITION CENTRE**

**JULY 24, 2013**

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NATIONAL PRESIDENT – ALZHEIMER'S AUSTRALIA**

**I AM DELIGHTED TO HAVE BEEN ASKED TO OFFICIALLY OPEN THIS IMPORTANT ANNUAL LEADERSHIP FORUM IN QUALITY DEMENTIA CARE AND TO LAUNCH THE MONTESSORI RESOURCE.**

**WHAT I PARTICULARLY LIKE ABOUT THIS FORUM IS THAT IT PROVIDES A GREAT OPPORTUNITY TO SHARE IDEAS BETWEEN THOSE WORKING IN AGED CARE.**

**AS A CONSUMER ORGANISATION, ALZHEIMER'S AUSTRALIA'S FOCUS IS ON QUALITY CARE; WE BELIEVE THAT IT STARTS WITH GAINING RESPECT FOR THE INDIVIDUAL WITH DEMENTIA.**

**IT IS THAT EMPHASIS ON RELATING TO THE PERSON THAT MAKES THE MONTESSORI LEARNING TECHNIQUES SO IMPORTANT.**

**AS AUSTRALIAN OF THE YEAR AND AS NATIONAL PRESIDENT OF ALZHEIMER'S AUSTRALIA I'VE HAD THE PRIVILEGE OF BEING WELCOMED INTO THE LIVES OF MANY PEOPLE ACROSS AUSTRALIA. THEY HAVE SHARED THEIR STORIES WITH ME AND THE REST OF THE COMMUNITY.**

**GOOD STORY TELLING IS AT THE HEART OF GOOD ADVOCACY. WE HAVE LEARNED THROUGH THE ALZHEIMER'S AUSTRALIA FIGHT DEMENTIA CAMPAIGN TO HARNESS THE POWER OF THE INDIVIDUAL STORY SO THAT THE WIDER COMMUNITY CAN BETTER UNDERSTAND WHAT IT IS LIKE FOR A PERSON TO LIVE WITH DEMENTIA.**

**IT TAKES COURAGE FOR PEOPLE WITH DEMENTIA TO TELL THEIR STORIES...SO MANY OF THE STORIES HAVE TOUCHED MY HEART...LIKE THE SCHOOLTEACHER....SHE WAS A FORMER SCHOOL PRINCIPLE AND I REMEMBER LOOKING AT HER THINKING WOW SHE WOULD HAVE BEEN A FORMIDABLE HEADMISTRESS...**

**THE SCHOOLTEACHER'S DIAGNOSIS OF YOUNGER ONSET DEMENTIA HAS ROBBED HER OF HER CAREER AND, AS SHE SAYS, MADE HER FEEL DIMINISHED AS A PERSON IN THE EYES OF HER FAMILY.**

**I WILL NEVER FORGET HER STORY....OR THE STORIES OF FAMILIES WHO ARE WRACKED WITH GUILT AFTER THE END OF LIFE CARE WISHES OF THEIR FAMILY MEMBERS WERE NOT RESPECTED.**

**I'VE FOUND MANY YOUNG PEOPLE OFTEN HAVE SPECIAL INSIGHTS INTO DEMENTIA THROUGH THEIR PARENTS AND GRANDPARENTS.**

**A FEW WEEKS AGO A YOUNG STUDENT SENT ME THE MOST WONDERFUL STORY ABOUT HER FAMILY AND HER GRANDFATHER WHO HAS ALZHEIMER'S WHICH SHE HAS WRITTEN AS PART OF HER YEAR 12 ENGLISH ASSIGNMENT. I CANNOT SAY MORE BECAUSE THE PROJECT IS STILL WITH THE EXAMINERS. BUT WHEN IT IS POSSIBLE OUR AIM IS TO PUBLISH HER ASSIGNMENT ON OUR WEBSITE.**

**SHE HAS REAL TALENT AND WRITES BEAUTIFULLY; I'VE TOLD HER I HOPE SHE FINDS A CAREER IN JOURNALISM.**

**WE HAVE TO ENSURE THROUGH FORUMS LIKE THIS THAT THERE IS AN UNDERSTANDING OF THE HUMOUR, FRUSTRATION AND DESPAIR WHICH ACCOMPANIES DEMENTIA AND HOW IMPORTANT IT IS TO RESPOND TO A PERSON'S NEEDS AND NOT JUST THE SYMPTOMS OF THE CONDITION.**

**IN SUPPORTING A PERSON WITH DEMENTIA THE EMPHASIS IS OFTEN ON CARING FOR THE PERSON RATHER THAN BUILDING ON THEIR STRENGTHS. FAMILIES AND CARE WORKERS BEGIN TO DO THINGS FOR THE PERSON WITH DEMENTIA AND MAKE DECISIONS FOR THEM LONG BEFORE THEY LOSE THE CAPACITY TO DO SUCH THINGS THEMSELVES.**

**AS WE APPROACH THE COMING FEDERAL ELECTION IT IS IMPORTANT TO DETERMINE WHICH OF OUR MAJOR POLITICAL PARTIES WILL SHOW STRONG LEADERSHIP TO IMPROVE THE LIVES OF THOSE LIVING WITH DEMENTIA AND THE PEOPLE CARING FOR THEM.**

**A KEY ELEMENT OF THE NATIONAL AGED CARE AND DISABILITY REFORM PROCESS IS ENSURING THE TRANSITION OF THE HOME AND COMMUNITY CARE PROGRAM FROM THE VICTORIAN GOVERNMENT TO THE COMMONWEALTH IS MANAGED SO THAT VITAL SERVICES AND FUNDING ARE NOT IMPACTED. CLIENTS AND THEIR FAMILIES NEED REASSURANCE THAT THEIR CURRENT SERVICE OFFERINGS WILL NOT BE REMOVED OR REDUCED.**

**AND WHILE WE NEED THIS SERVICE TO CONTINUE, WE DESPERATELY NEED MORE FUNDING FOR COMMUNITY CARE AND RESIDENTIAL CARE SERVICES.**

**WE ALSO NEED A DRAMATIC CHANGE IN OUR SOCIETAL CULTURE AND SOCIAL ATTITUDES TO PEOPLE WITH DEMENTIA AND OLDER PEOPLE MORE GENERALLY.**

**IT IS THE COMBINATION OF SOCIAL ACTION AND IMPROVED ACCESS TO SERVICES THAT THE ALZHEIMER'S AUSTRALIA FIGHT DEMENTIA ELECTION CAMPAIGN DOCUMENT ADDRESSES.**

**AND IF THE PHILOSOPHY THAT UNDERPINS MONTESSORI METHODS IS TO THRIVE, I THINK WE NEED TO SET A DIFFERENT AGENDA.**

**THERE ARE FOUR ELEMENTS TO THIS AGENDA:**

- **BETTER SOCIAL ACTION AND ENGAGEMENT**
- **BETTER COMMUNITY CARE CHOICES,**
- **BETTER CONSUMER-DIRECTED CARE AND**
- **BETTER QUALITY RESIDENTIAL CARE.**

**BETTER SOCIAL ACTION AND ENGAGEMENT NEEDS TO BE PROMOTED THROUGH DEMENTIA-FRIENDLY COMMUNITIES AND DEMENTIA-FRIENDLY ORGANISATIONS. MEDIA SUPPORT TO PROMOTE THESE TWO APPROACHES WOULD BE INVALUABLE.**

**PEOPLE NEED TO RECOGNISE LIFE GOES ON AFTER A DIAGNOSIS OF DEMENTIA AND THAT PEOPLE WITH DEMENTIA AND THEIR FAMILY CARERS NEED TO CONTINUE THEIR LIFE IN THE COMMUNITY AND TO HAVE ACCESS TO THE SERVICES WE ALL EXPECT TO RECEIVE – WHETHER FROM BANKS, CENTRELINK OR RETAILERS.**

**I UNDERSTAND FROM A NUMBER OF OUR ALZHEIMER'S AUSTRALIA STATE AND TERRITORY ORGANISATIONS THAT THERE HAS BEEN SIGNIFICANT INTEREST IN THE TWO DOCUMENTS RELEASED IN MARCH BY ALZHEIMER'S AUSTRALIA ON DEMENTIA-FRIENDLY SOCIETIES AND DEMENTIA-FRIENDLY ORGANISATIONS.**

**I WAS DELIGHTED TO LEARN AT OUR JUNE NATIONAL BOARD MEETING THAT THE ANZ IS ALREADY USING ALZHEIMER'S AUSTRALIA'S RESOURCE PACKAGE IN THEIR STAFF TRAINING PROGRAMS.**



**OVER THE NEXT 12 MONTHS WE WILL BE SEEKING TO ENGAGE WITH LOCAL GOVERNMENTS AND KEY ORGANISATIONS TO PROMOTE THE MESSAGE THAT THEY TOO CAN BE DEMENTIA-FRIENDLY.**

**IN THIS WAY I THINK WE CAN MAKE A CONTRIBUTION TO REDUCING THE STIGMA AND SOCIAL ISOLATION THAT A DIAGNOSIS OF DEMENTIA BRINGS TO THE INDIVIDUAL AND THEIR FAMILIES.**

**IT'S CRUCIAL THAT PEOPLE WITH DEMENTIA AND THEIR FAMILY CARERS HAVE BETTER COMMUNITY CARE CHOICES**

**FROM A CONSUMER PERSPECTIVE ONE OF THE MAIN ELEMENTS IN *LIVING LONGER. LIVING BETTER.* IS THE EXPANSION OF COMMUNITY CARE PACKAGES TO GIVE PEOPLE THE CHOICE OF REMAINING AT HOME LONGER.**

**IN THE NEXT 10 YEARS COMMUNITY CARE PLACES WILL MORE THAN DOUBLE FROM 64,800 TO 144,469. IF PEOPLE WITH DEMENTIA ARE TO HAVE A CHOICE OF LIVING AT HOME LONGER, THEN MORE FLEXIBLE COMMUNITY CARE SERVICES ARE IMPERATIVE.**

**A PREREQUISITE OF CHOICE IS INFORMATION AND ASSISTANCE SO THAT A PERSON CAN FIND THEIR WAY THROUGH THE SERVICE MAZE.**

**ALZHEIMER'S AUSTRALIA HAS WELCOMED THE FUNDING BY THE COMMONWEALTH GOVERNMENT AS PART OF *LIVING LONGER. LIVING BETTER.* OF YOUNGER ONSET DEMENTIA KEY WORKERS WHO WILL PROVIDE SUPPORT AND ASSISTANCE TO YOUNGER PEOPLE WITH DEMENTIA AND THEIR FAMILIES, IDENTIFY SERVICE GAPS AND WORK WITH SERVICES ON SERVICE DEVELOPMENT.**

**THE VICTORIAN GOVERNMENT HAS ALSO SHOWN GREAT INITIATIVE IN HELPING US TACKLE THE DEMENTIA CHALLENGE.**

**IN THE PAST TWO YEARS THEIR SUPPORT HAS ENABLED ALZHEIMER'S AUSTRALIA VIC TO EXPAND MUCH-NEEDED SERVICES INTO REGIONAL AREAS, AS WELL AS HELPING THE ORGANISATION REALISE ITS VISION OF A CENTRE FOR DEMENTIA LEARNING EXCELLENCE THAT WILL BE OPENING LATER THIS YEAR AT PARKVILLE.**

**AN IMPORTANT COMPONENT OF OUR FIGHT DEMENTIA CAMPAIGN ELECTION DOCUMENT IS THE PROPOSAL TO EXTEND THIS CAPACITY FOR FACE-TO-FACE ASSISTANCE AND SUPPORT THROUGH KEY WORKERS TO OLDER PEOPLE WITH DEMENTIA.**

**ALZHEIMER'S AUSTRALIA HAS BEEN AN ADVOCATE FOR CONSUMER-DIRECTED CARE FOR WELL OVER A DECADE AND CONSUMERS HAVE BEEN REQUESTING THIS KIND OF SUPPORT FOR MANY YEARS.**

**WE ARE DELIGHTED THIS PRINCIPLE HAS BEEN EMBEDDED IN THE *LIVING LONGER. LIVING BETTER.* PACKAGE OF AGED CARE REFORMS.**

**HOWEVER PERSON-CENTRED CARE CAN ONLY BECOME A REALITY IF THE PARTNERSHIP BETWEEN SERVICE PROVIDER AND CONSUMER IS EQUAL.**

**THE PERSON WITH DEMENTIA AND THEIR FAMILY CARER NEED TO KNOW WHAT RESOURCES ARE AVAILABLE TO MEET THEIR GOALS.**

**ON THE BASIS OF THAT UNDERSTANDING, A PERSON CAN WORK WITH A SERVICE PROVIDER TO MAKE SURE SENSIBLE CHOICES ARE MADE ABOUT THE SERVICES THAT ARE MOST NEEDED AND DECISIONS TAKEN TO DETERMINE THE MOST APPROPRIATE SERVICE PROVIDER AND WHEN, WHERE AND HOW THE SERVICES WILL BE DELIVERED.**

**FROM A CONSUMER PERSPECTIVE, I SEE CONSUMER-DIRECTED CARE AND CHOICE AS BEING CENTRAL TO EMPOWERMENT.**

**IF WE ARE NOT MORE RADICAL IN OUR APPROACH TO SEEKING POWER FOR THE PERSON WITH DEMENTIA AND THEIR FAMILIES, WE SIMPLY WON'T SUCCEED IN ACHIEVING BETTER CARE OUTCOMES AND MORE FLEXIBLE SERVICES THAT ENABLE PEOPLE TO LIVE AT HOME FOR AS LONG AS POSSIBLE.**

**BETTER QUALITY RESIDENTIAL CARE HAS BEEN A LONG-STANDING CONCERN OF PEOPLE WITH DEMENTIA AND THEIR FAMILY CARERS.**

**THESE WERE COMPREHENSIVELY DOCUMENTED IN A REPORT BY ALZHEIMER'S AUSTRALIA AND RELEASED IN APRIL 2012.**

**FROM TIME TO TIME IT HAS BEEN SUGGESTED TO ME THAT ALZHEIMER'S AUSTRALIA HAS EXAGGERATED CONCERNS ABOUT RESIDENTIAL CARE. THAT SIMPLY IS NOT TRUE.**

**I'M WELL AWARE THAT THERE ARE MANY EXCELLENT AGED CARE FACILITIES BUT THERE ARE JUST TOO MANY STORIES FROM CONSUMERS ABOUT POOR QUALITY CARE.**

**AND IN ANY EVENT ONE CASE OF ABUSE AND LOSS OF HUMAN RIGHTS IS ONE TOO MANY AND CLEARLY, THERE ARE MANY MORE THAN ONE!**

**OVER NEARLY TWO YEARS ALZHEIMER'S AUSTRALIA HAS REGISTERED SERIOUS CONCERN ABOUT THE OVER-PRESCRIPTION OF ANTI-PSYCHOTICS IN RESIDENTIAL CARE.**

**MOST RECENT RESEARCH SUGGESTS THAT 70 PER CENT OF RESIDENTS HAVE BEEN PRESCRIBED PSYCHOTROPIC MEDICATION OF WHICH ANTI – PSYCHOTIC MEDICATIONS ACCOUNTED FOR 27 PER CENT. THERE IS PARTICULAR CONCERN ABOUT MULTIPLE PSYCHOTROPIC USE. THERE HAS NOT YET BEEN A SERIOUS RESPONSE TO THESE CONCERNS.**

**THE FIVE LATELINE ABC PROGRAMS IN THE LAST 12 MONTHS WHICH HAVE DOCUMENTED INDIVIDUAL CASES OF EXTREME POOR QUALITY CARE IN SOME RESIDENTIAL FACILITIES HAVE CONVINCED ME THAT SOMETHING NEEDS TO BE DONE.**

**IT IS NOT JUST A QUESTION OF FUNDING, IMPORTANT THOUGH AS THAT IS. THERE IS A NEED FOR A CHANGE OF CULTURE IN RESIDENTIAL CARE.**

**I HAVE RECEIVED DISTURBING EVIDENCE OF NURSING HOME STAFF WHO HAVE MADE INAPPROPRIATE REMARKS ON FACEBOOK AND COMPROMISED THE DIGNITY AND PRIVACY OF THOSE FOR WHOM THEY CARE. AND I HAVE TAKEN THIS UP WITH THE APPROPRIATE DEPARTMENT OF HEALTH AND AGEING.**

**I KNOW MOST OF OUR AGED CARE STAFF IS DOING THEIR BEST AND WORKING HARD TO CARE FOR OLDER PEOPLE. OFTEN THEY ARE PAID LESS THAN SIMILAR POSITIONS IN THE HOSPITAL SYSTEM.**

**BUT AGAIN THIS IS NOT JUST A MATTER OF FUNDING AND IT'S NOT JUST A MATTER OF TRAINING – ALTHOUGH THAT MAY HELP. IT IS A FAILURE OF LEADERSHIP AT ALL LEVELS AND AN INSTITUTIONAL CULTURE THAT GENERATES FEAR.**

- **THE FEAR A RESIDENT HAS THAT THEY MAY BE PUNISHED FOR COMPLAINING**
- **THE FEAR A FAMILY CARER HAS THAT THEY MAY BE TOLD TO TAKE THEIR FAMILY MEMBER ELSEWHERE**
- **THE FEAR OF WHAT MIGHT HAPPEN TO THE RESIDENT WHEN THE FAMILY CARER IS NOT THERE.**

**THESE ARE COMPLEX ISSUES FOR WHICH THERE ARE NO SIMPLE ANSWERS.**

**AT THE ALZHEIMER'S AUSTRALIA NATIONAL CONFERENCE IN MARCH THIS YEAR, THERE WAS A PRESENTATION FROM CATHERINE MORLEY, CEO OF RURAL NORTH WEST HEALTH IN VICTORIA WHO I UNDERSTAND ALSO PRESENTED AT THIS FORUM LAST YEAR.**



**SHE SPOKE ABOUT HER EXPERIENCE IN IMPLEMENTING AN INNOVATIVE PERSON-CENTRED APPROACH TO CARE WITHIN WATTLE CRESCENT – A 15-BED SECURE DEMENTIA SUPPORT AGED CARE UNIT. THE CARE WAS BASED ON MONTESORRI PRINCIPLES, REORIENTING CARE AWAY FROM DISABILITY AND TOWARDS CAPABILITY.**

**THE PROJECT INCLUDED STAFF TRAINING TO SUPPORT CULTURAL CHANGE AND CHANGES TO THE PHYSICAL ENVIRONMENT. IT IS AMAZING TO SEE WHAT THEY HAVE ACHIEVED IN THE LAST TWO YEARS.**

**ONE OF THE MOST POWERFUL SIGNS OF CHANGE WAS A SIMPLE QUESTION TO THEIR STAFF: “WOULD YOU LIKE TO LIVE HERE IF YOU HAD DEMENTIA?”**

**AT THE START OF THEIR PROJECT ONLY 8 PER CENT OF STAFF SAID YES TO THIS QUESTION. BY THE COMPLETION OF THE PROJECT, THIS HAD INCREASED TO 80 PER CENT.**

**AT THE START OF THE PROJECT 78 PER CENT OF RESIDENTS WERE ON ANTI-PSYCHOTICS, AT FOLLOW UP 99 PER CENT HAD BEEN TAKEN OFF THESE MEDICATIONS.**

**THIS IS NOT THE ONLY FACILITY DOING EXCITING THINGS IN DEMENTIA CARE AND THERE WILL BE MORE PRESENTATIONS TODAY FROM SERVICES SHARING THE GOOD WORK THEY ARE DOING.**

**BUT IT IS EXAMPLES LIKE WATTLE CRESCENT THAT ILLUSTRATE THE IMPORTANCE OF LEADERSHIP AND OF TAKING A NEW APPROACH TO HOW WE THINK ABOUT CARING FOR PEOPLE WITH DEMENTIA.**

**PERHAPS IT IS INHERENT IN INSTITUTIONAL CARE THAT TRANSPARENCY IS HARD TO ACHIEVE. QUALITY INDICATORS AND MONITORING OF QUALITY OUTCOMES IS STILL A WAY OFF IN THE REFORM PROCESS. MEANWHILE CONSUMERS ARE LEFT IN THE DARK ABOUT THE QUALITY OF CARE THAT IS AVAILABLE.**

**WHILE WE ARE WAITING FOR THESE INDICATORS TO BECOME A REALITY, WE MUST STOP COMING UP WITH EXCUSES FOR THE EXAMPLES OF POOR QUALITY CARE. LET'S TAKE INNOVATIVE APPROACHES TO CARE AND MAKE SURE WE GIVE THE PERSON WITH DEMENTIA THE RESPECT THEY DESERVE.**

**FOR MY PART I HAVE GIVEN A COMMITMENT THAT I WILL SEEK THE PERMISSION OF PEOPLE WHO HAVE WRITTEN TO ME, AND NO DOUBT WILL CONTINUE TO WRITE TO ME ABOUT THEIR EXPERIENCES IN AGED CARE FACILITIES, CONSUMERS HAVE BEEN REQUESTING THIS KIND OF SUPPORT FOR MANY YEARS. TO PUT THEIR STORIES ON THE ALZHEIMER'S AUSTRALIA WEBSITE.**

**FINALLY LADIES AND GENTLEMEN, I SUGGEST WE NEED HOPE FOR THE FUTURE. THIS HAS TO COME THROUGH INCREASED INVESTMENT IN DEMENTIA RESEARCH.**

**FOR NEARLY TWO YEARS NOW ALZHEIMER'S AUSTRALIA HAS  
ADVOCATED FOR AN ADDITIONAL \$200 MILLION OVER FIVE YEARS FOR  
DEMENTIA RESEARCH TO LIFT FUNDING FROM ITS CURRENT GROSSLY  
INADEQUATE LEVELS.**

**THE CONSEQUENCE OF INADEQUATE FUNDING IS NOT ONLY FEWER  
RESEARCH PROJECTS BUT ALSO A LACK OF INVESTMENT IN DEMENTIA  
RESEARCH CAPACITY FOR THE FUTURE. THERE IS NO SIGNAL TO THE  
BRIGHTEST AND EMERGING RESEARCHERS THAT BRAIN HEALTH AND  
DEMENTIA ARE THE MAJOR AREAS OF CHALLENGE IN THIS CENTURY.**

**ALZHEIMER'S AUSTRALIA HAS A CLEAR AGENDA FOR THE NEXT THREE  
YEARS AND I HOPE BOTH MAJOR PARTIES RESPOND TO IT POSITIVELY.**

**ADDITIONAL FUNDING IS NEEDED BUT SO TOO IS A CHANGE OF CULTURE  
AND SOCIAL ATTITUDES.**

**LEADERSHIP IS ABOUT CHANGING ATTITUDES AND SHOWING THE WAY TO DO BETTER. IT DOESN'T ALWAYS COST MONEY BUT IT CERTAINLY INVOLVES PERSONAL COMMITMENT AT THE TOP.**

**EQUALLY WE CAN ALL BE LEADERS WITHIN OUR OWN SPHERES OF INFLUENCE AND I PUT THE CHALLENGE OUT TO YOU ALL TODAY AND ASK YOURSELF: *"AM I DOING AS MUCH AS I CAN TO IMPROVE THE QUALITY OF LIFE OF THE PEOPLE LIVING WITH DEMENTIA TO WHOM I PROVIDE A SERVICE?"***

**THAT'S WHAT WE ARE LOOKING FOR... A POLITICAL, COMMUNITY AND SERVICE FRAMEWORK IN WHICH MONTESSORI METHODS AND THE OTHER ELEMENTS OF GOOD QUALITY WILL BECOME THE NORM RATHER THAN THE EXCEPTION.**

**THANK YOU.**