

I WOULD LIKE TO THANK THE ORGANISERS, GARY BARNIER AND THE TEAM AT DOMAIN PRINCIPAL GROUP FOR THE INVITATION TO SPEAK ON HOW AGED CARE PROVIDERS CAN EMPOWER CONSUMERS IN RESIDENTIAL AGED CARE.

AS A HUMBLE POLICY PERSON, I HESITATE TO SHARE MY IDEAS WITH A WELL INFORMED AUDIENCE LIKE THIS. BUT THE THREE MESSAGES THAT PERMEATE WHAT I WILL SAY TO YOU TODAY ARE THESE.

FIRST, THAT THERE IS A VAST DIFFERENCE BETWEEN HAVING CONSUMERS AT THE CENTRE OF A CARE PLAN AND HAVING CONSUMERS AS PARTNERS.

SECOND, THAT ALL THE STAKEHOLDERS IN AGED CARE INCLUDING CONSUMERS HAVE NOT THOUGHT ENOUGH ABOUT RIGHTS BASED APPROACHES AND EMPOWERMENT.

THIRDLY, THAT A PRECONDITION FOR EMPOWERING CONSUMERS IS EMPOWERING AND SUPPORTING STAFF.

WE HAVE BEEN TALKING ABOUT CHOICE AND QUALITY OF LIFE IN AGED CARE SINCE THE MID 1980S.

AT THE TIME WHEN I CHAIRED THE NURSING HOMES AND HOSTELS REVIEW IN 1985, THE FOCUS WAS ON "HOLISTIC CARE"; CARE WHICH MET THE

PHYSICAL, SOCIAL, AND SPIRITUAL NEEDS OF THE PERSON. A CONCEPT WHICH NOT SO VERY DIFFERENT FROM PERSON CENTRED CARE.

THERE HAS ALSO BEEN A LONG STANDING FOCUS ON CHOICE AND FLEXIBILITY OF SERVICES THROUGH AN EXPANSION OF COMMUNITY CARE SERVICES SO THAT OLDER PEOPLE HAVE A GENUINE CHOICE IN STAYING AT HOME.

THERE HAS BEEN A DESIRE TOO, TO GIVE PEOPLE GREATER CHOICE WITHIN RESIDENTIAL CARE AND TO PROVIDE A HOMELIKE ENVIRONMENT.

IT HAS BEEN A LONG JOURNEY BUT I AM PLEASED THAT THE 2012 AGED CARE REFORMS MARK A SHIFT IN THE ROLE OF CONSUMERS IN THE AGED CARE SYSTEM. AND THIS SHIFT IS NOT JUST A CHANGE IN THE RHETORIC BUT THE REFORMS MEAN THAT ALL NEW COMMUNITY CARE PACKAGES WILL BE OFFERED AS CDC. THE IDEA IS THAT CDC ENABLES CONSUMERS TO BE AN EQUAL PARTNER IN THE CARE AND PLANNING PROCESS.

AND THERE IS THE FIRST REFERENCE I CAN RECALL IN A POLICY DOCUMENT TO CDC IN RESIDENTIAL AGED CARE.

FOR WELL OVER 10 YEARS, ALZHEIMER'S AUSTRALIA HAS ADVOCATED FOR A CONSUMER DIRECTED APPROACH TO CARE.

THE OBJECTIVE WHICH WE REFINED THROUGH RESEARCH AND CONSUMER CONSULTATIONS WAS ADOPTED BY GOVERNMENT IN 2009 IN THE TRIAL OF THE CDC IN PACKAGES, NAMELY:

“CARE RECIPIENTS AND THEIR CARERS SHOULD HAVE GREATER CONTROL OVER THEIR OWN LIVES BY ALLOWING THEM, TO THE EXTENT THEY ARE CAPABLE AND WISH TO DO SO, TO MAKE CHOICES ABOUT THE TYPES OF CARE SERVICES THEY ACCESS AND THE DELIVERY OF THOSE SERVICES, INCLUDING WHO WILL DELIVER THE SERVICES AND WHEN”.

THE OUTCOMES CONSUMERS WISH TO ACHIEVE THROUGH CDC INCLUDE:

1. A BETTER MATCH BETWEEN THEIR GOALS AND THE CARE AND SUPPORT PROVIDED.
2. GREATER FLEXIBILITY IN THE SERVICES PROVIDED.
3. THE CAPACITY TO ACCESS THOSE PROVIDERS BEST POSITIONED TO PROVIDE THE SERVICES REQUIRED.
4. TRANSPARENCY IN THE FUNDS AVAILABLE TO THE INDIVIDUAL AND THE AMOUNT USED FOR ADMINISTRATION.

CDC AND PERSON CENTRED CARE ARE OFTEN USED INTERCHANGEABLY.

THERE IS, HOWEVER, A VAST DIFFERENCE BETWEEN HAVING CONSUMERS AT THE CENTRE OF A CARE PLAN AND HAVING CONSUMERS AS PARTNERS.

I WOULD ARGUE THAT MANY RESIDENTIAL AGED CARE PROVIDERS ALREADY IMPLEMENT PERSON CENTRED CARE. BUT TRUE PARTNERSHIPS WITH CONSUMERS IN AGED CARE ARE MUCH MORE RARE.

THE MOVE TOWARDS CDC NECESSITATES A SIGNIFICANT SHIFT IN THE CULTURE AND ATTITUDES OF BOTH SERVICE PROVIDERS AND CONSUMERS IN THE AGED CARE SECTOR – A SHIFT TOWARDS ENGAGING WITH CONSUMERS AND THEIR FAMILY MEMBERS AND FOCUSING ON OUTCOMES AND ACHIEVING GOALS RATHER THAN PROCESSES.

THIS MEANS THAT PROVIDERS HAVE TO FOCUS ON WHAT IS IMPORTANT TO CONSUMERS AND HOW CONSUMERS CAN BE SUPPORTED TO MEET THEIR OWN GOALS RATHER THAN PROVIDING THE CARE WE THINK IS BEST FOR CONSUMERS.

THIS CAN BE A DIFFICULT BALANCE AS THE SERVICE PROVIDER HAS A DUTY OF CARE AND HAS TO MANAGE RISK WHILE ALSO RECOGNISING THAT IT IS A PERSONS RIGHT TO CHOOSE.

IT IS THE SHIFT IN CULTURE THAT WILL EMPOWER CONSUMERS TO MAKE CHOICES AND BE ACTIVE PARTICIPANTS IN THEIR CARE AND FOR FAMILY MEMBERS AND CARERS TO FEEL VALUED.

IT WILL REQUIRE ALL OF US TO RETHINK THE WAYS IN WHICH WE PROVIDE CARE FOR PEOPLE LIVING WITH DEMENTIA.

THE WAY CDC HAS BEEN APPLIED IN AGED CARE IS STILL SOMEWHAT LIMITED COMPARED TO WHAT HAS BEEN ADOPTED IN THE DISABILITY SECTOR AND IN SOME CASES OVERSEAS.

I AM HOPEFUL THAT WE WILL MOVE TO MORE INNOVATIVE APPROACHES TO CDC. CHOICES SUCH AS CASHING OUT RESPITE CARE FUNDING, CONSUMERS POOLING FUNDING TO PURCHASE SERVICES AND PARTICIPATION IN SOCIAL ACTIVITIES.

FOR EXAMPLE, IF WE ARE TO ACHIEVE CHOICE AND FLEXIBILITY FOR CONSUMERS WE NEED TO RETHINK THE RELATIONSHIP BETWEEN COMMUNITY AND RESIDENTIAL CARE. AT THE MOMENT IT IS ONE OR THE OTHER.

I HAVE LONG HAD A VIEW THAT WE CAN DO MORE TO PROMOTE RESPITE IN RESIDENTIAL CARE SO THAT CONSUMERS HAVE THE OPTION OF PLANNED RESPITE IN REGULAR BLOCKS OF SEVERAL WEEKS OR MORE IN CLUSTERS SEPARATE FROM LONG TERM CARE. THIS WOULD GIVE CONSUMERS THE CAPACITY TO PLAN CARE IN AN ENVIRONMENT THAT PRESENTS OPPORTUNITIES FOR SOCIAL ENGAGEMENT FOR THE PERSON WITH DEMENTIA.

RESIDENTIAL RESPITE HAS LONG SERVED AS A TRANSITION FOR SOME CONSUMERS TO LONG-TERM CARE, BUT THERE ARE MANY OTHERS WITH HIGHER LEVEL CARE NEEDS FOR WHOM RESPITE IS NEEDED AND FOR WHOM THE LONG-TERM CARE ENVIRONMENT IS THREATENING OR INAPPROPRIATE.

I WAS IN SOUTH AUSTRALIA RECENTLY AND LEARNT ABOUT VITA. THIS IS AN INNOVATIVE PROJECT WHICH RECOGNISES THE CAPACITY FOR OLDER PEOPLE TO RESTORE THEIR LIVES. IT OFFERS A NEW CONCEPT IN REHABILITATION - THIRTY SUB-ACUTE BEDS MANAGED BY ADELAIDE HOSPITAL, THIRTY TRANSITION BEDS MANAGED BY AGED CARE HOMES AND THIRTY LONG TERM CARE FUNDED BEDS MANAGED BY AGED CARE HOMES THAT ARE FOR USE ON A SHORT TERM PLANNED CARE BASIS. THE APPROACH IS COMBINED WITH TEACHING AND RESEARCH TOO.

THIS EXCITING PROJECT COMBINES MANY OF THE ELEMENTS WE FIND SO HARD TO BRING TOGETHER. NAMELY KEEPING OLDER PEOPLE OUT OF HOSPITALS, ENSURING A BETTER TRANSITION BACK TO THE COMMUNITY BACK FROM HOSPITAL AND HAVING ACCESS TO RESIDENTIAL CARE AS AND WHEN NEEDED RATHER THAN ON A PERMANENT LONG TERM BASIS.

IT IS IMPORTANT TO BE AMBITIOUS IN EMPOWERING RESIDENTS WHILE BEING MINDFUL OF CARE RESPONSIBILITIES AND THE RESOURCE CONSTRAINTS SO WE DO NOT SET OURSELVES UP FOR FAILURE. THIS IS TRULY A DIFFICULT DEBATE.

IMPLEMENTING CDC WITHIN RESIDENTIAL AGED CARE WILL BE PARTICULARLY CHALLENGING. BUT I THINK IT COMES DOWN TO SIMPLE PRINCIPLES:

- INVOLVING CONSUMERS IN CARE PLANNING
- DEVELOPING A FEEDBACK MECHANISM SO THAT THE CARE RECIPIENTS AND FAMILIES CAN PROVIDE INPUT INTO THE ORGANISATION AND CONTINUOUS IMPROVEMENT
- PROVIDING STAFF WITH THE TRAINING AND SUPPORT THEY NEED TO PROVIDE CARE WITHIN THE CDC ENVIRONMENT
- GREATER TRANSPARENCY IN CARE OUTCOMES.

THERE ARE MANY DIFFICULT ISSUES TO WORK THROUGH INCLUDING:

- HOW TO DEAL WITH CONSUMER DEMANDS IN CONSTRAINED CIRCUMSTANCES, FOR EXAMPLE, TRANSPORT TO OUTSIDE ACTIVITIES INCLUDING SHOPPING, CINEMAS ETC.
- THE RIGHT BALANCE OF THE RELATIONSHIP BETWEEN STAFF AND RESIDENTS. ARE THERE BOUNDARIES THAT SHOULD NOT BE CROSSED AND HOW WELL HAVE WE ARTICULATED THEM TO GUIDE STAFF?
- ASSISTING STAFF TO UNDERSTAND BETTER HOW THEY CAN COMMUNICATE WITH THOSE WITH DEMENTIA.

- ADOPTING ENVIRONMENTS AND DESIGN THAT APPROPRIATE TO DEMENTIA CARE.
- ENSURING TRAINING IN PSYCHO-SOCIAL APPROACHES THAT REDUCE TO THE MINIMUM THE USE OF RESTRAINT.
- IMPROVING THE TRANSPARENCY OF CONSENT ARRANGEMENTS WHERE RESTRAINT IS NECESSARY.
- THE EXTENT TO WHICH FLEXIBILITY IN FOOD SERVICES AND PERSONAL CARE CAN BE ACCOMMODATED WITHIN AVAILABLE RESOURCES.
- PROVIDING ACCESS TO MEDICAL TREATMENT AND PALLIATIVE CARE SERVICES THAT MIGHT OBTAIN ADMISSION TO HOSPITAL.
- PROVIDING APPROPRIATE CARE AND SUPPORT FOR PEOPLE FROM CALD, INDIGENOUS AND GAY AND LESBIAN COMMUNITIES.
- ENSURING THAT THE END OF LIFE WISHES OF THE RESIDENT ARE RESPECTED.
- PROVIDING SUPPORT TO CARERS THROUGHOUT THE DEMENTIA JOURNEY INCLUDING BEREAVEMENT SUPPORT

AND PERHAPS MOST IMPORTANTLY HOW WE SUPPORT PEOPLE WITH DEMENTIA AND CARERS TO TAKE A NEW APPROACH TO HOW THEY ARE INVOLVED IN CARE AND TO BE EMPOWERED TO STAND UP FOR THEIR RIGHTS IN AGED CARE.

ISSUES RELATING TO SEXUALITY ILLUSTRATE BETTER THAN ALMOST ANY OTHER THE CHALLENGE OF REALISING CHOICE WITHIN RESIDENTIAL CARE.

POORLY HANDLED THE ISSUE IMPACTS ON THE QUALITY OF LIFE OF THE PERSON, AND PUTS STRESS ON THE FAMILY AND STAFF.

YET PEOPLE NO MATTER WHAT THEIR AGE OR DISABILITY HAVE A NEED FOR SEXUAL EXPRESSION – SOMETHING THAT PEOPLE OFTEN FAIL TO UNDERSTAND.

WE ALSO NEED TO RECOGNISE THAT IF WE WANT TO PARTNER WITH CONSUMERS THEY NEED TO HAVE A LARGER ROLE IN THE AGED CARE ORGANISATIONS IN ORDER TO PROVIDE FEEDBACK AND GUIDANCE ON CARE PRACTICES.

THERE ARE A NUMBER OF INNOVATIVE APPROACHES WHICH HAVE BEEN TRIED BOTH IN AUSTRALIA AND OVERSEAS TO INVOLVE CONSUMERS AND THEIR FAMILIES IN CARE ORGANISATIONS INCLUDING

- INVOLVING CARERS AND FAMILY MEMBERS AT A LEADERSHIP LEVEL OR AS MEMBERS OF AN ONGOING GROUP OR SPECIFIC FOCUS GROUP TO IMPROVE CARE.
- THE USE OF QUESTIONNAIRES TO GAIN THE FAMILY MEMBERS AND CARERS VIEWS AND TO PROVIDE INPUT INTO CONTINUOUS IMPROVEMENT.
- RESIDENT GROUPS OR COMMITTEES WHO PROVIDE CARE STAFF AND MANAGEMENT WITH INFORMATION ON THE RESIDENT EXPERIENCE OF CARE.

- THE DEVELOPMENT OF QUALITY INDICATORS TO ENSURE THAT RESIDENTS ARE RECEIVING CARE, SUPPORTS AND SERVICES THAT DIRECTLY MEETS THEIR NEEDS.
- INVOLVING CONSUMERS IN THE RECRUITMENT OF NEW STAFF.

NOTHING IS EVER TOTALLY NEW AND SOME OF THESE THINGS ARE ALREADY HAPPENING IN AUSTRALIA. BUT WE NEED TO THINK ABOUT HOW WE CAN ACHIEVE GREATER TRANSPARENCY OF INFORMATION AND INVOLVEMENT OF CONSUMERS TO SUPPORT CHOICE AND EMPOWERMENT.

A PRECONDITION FOR EMPOWERING CONSUMERS IS EMPOWERING AND SUPPORTING STAFF.

IT IS IMPOSSIBLE FOR STAFF TO SUPPORT CHOICE, FLEXIBILITY AND PROVIDE HIGH QUALITY CARE IF THEY THEMSELVES ARE NOT ADEQUATELY SUPPORTED.

BOTH CONSUMERS AND POLICY MAKERS HAVE IDENTIFIED THE NEED FOR REFORM AND IMPROVEMENT IN CONDITIONS FOR AGED CARE STAFF. ISSUES SUCH AS WAGE PARITY, CLEAR CAREER PATHWAYS, ACCESS TO TRAINING AND STAFFING LEVELS/AND SKILLS MIX ARE ALL IMPORTANT COMPONENTS OF THIS ISSUE.

ALZHEIMER'S AUSTRALIA HAS BEEN SUPPORTIVE OF INITIATIVES TO IMPROVE WORKPLACE CONDITIONS INCLUDING THE WORKFORCE ELEMENT OF THE AGED CARE REFORMS.

WE BELIEVE THAT THE \$1.1 BILLION WORKFORCE SUPPLEMENT SHOULD BE USED TO ADDRESS THESE WORKFORCE PRIORITIES AND IN A WAY THAT IS TRANSPARENT AND ACCOUNTABLE.

BUT IF AN ACCOUNTABLE MECHANISM CAN NOT BE FOUND THEN THE MONEY SHOULD BE USED FOR OTHER PURPOSES THAT ARE TRANSPARENT AND WILL LEAD TO IMPROVED ACCESS TO QUALITY CARE INCLUDING EXPANDING COMMUNITY CARE AND INDEXING FUNDING FOR COMMUNITY CARE PROPERLY.

BUT THE WORKFORCE SUPPLEMENT, HOWEVER ADMINISTERED WILL NOT SOLVE ALL THE CHALLENGES.

WE NEED TO ENSURE THAT AGED CARE IS AN ATTRACTIVE FIELD FOR NEW CARE WORKERS AND NURSING STAFF. THERE NEEDS TO BE OPPORTUNITIES FOR CAREER DEVELOPMENT AND HIGH QUALITY TRAINING.

THERE ARE NO EASY SOLUTIONS- BUT I THINK SOME OF THE RECENT INITIATIVES AROUND TEACHING NURSING HOMES AND COLLABORATIONS BETWEEN NURSING HOMES AND UNIVERSITIES ARE STEPS IN THE RIGHT

DIRECTION. I KNOW FOR EXAMPLE, DOMAIN HAS BEEN DOING SOME INTERESTING WORK WITH UNIVERSITY OF QUEENSLAND ON THE ADOPTION OF QUALITY OF LIFE INDICATORS IN AGED CARE

A LARGE PART OF THE CHALLENGES WE FACE- WHETHER IT BE IN EMPOWERING CONSUMERS OR STAFF IS IN REGARD TO CULTURAL CHANGE- AND WITHIN AGED CARE IT IS ESSENTIAL THAT THE DESIRE FOR CULTURAL CHANGE AND THE FOCUS ON QUALITY STARTS WITH THE LEADERSHIP OF THE ORGANISATION.

I WOULD LIKE TO COMMEND THE DOMAIN PRINCIPAL GROUP FOR BEING PROACTIVE ABOUT THEIR DESIRE TO PROVIDE HIGH QUALITY DEMENTIA CARE.

YOUR STAFF AND ORGANISATION AS A WHOLE HAS SHOWN A WILLINGNESS AND PREPAREDNESS TO EXAMINE THE CULTURE OF YOUR ORGANISATION AND PROMOTE AN OPEN RELATIONSHIP WITH STAFF AND PEOPLE LIVING WITH DEMENTIA.

THE NEW PARTNERSHIP BETWEEN ALZHEIMER'S AUSTRALIA AND DOMAIN PRINCIPAL GROUP WILL ADOPT A WHOLE OF ORGANISATION APPROACH TO TRAINING AND PROVIDE A BETTER CARE AND WORKING ENVIRONMENT FOR PEOPLE LIVING WITH DEMENTIA, FAMILY MEMBERS AND CARERS AND STAFF.

YOU HAVE ALREADY UNDERTAKEN CONSIDERABLE STEPS TO ENSURE THE SUCCESS OF THIS PROJECT AND WE AT ALZHEIMER'S AUSTRALIA LOOK FORWARD TO WORKING WITH YOU OVER THE NEXT TWO YEARS AND BEYOND.

YOU WILL LEARN A LOT MORE FROM OTHERS ABOUT THE PROPOSED APPROACH SO I WILL SAY NO MORE.

THE PROJECT COMES AT A VERY EXCITING TIME IN TERMS OF AGED CARE REFORM. THERE IS HOPEFULLY A SEA CHANGE IN RECOGNISING THE IMPORTANCE OF EMPOWERING CONSUMERS TO MAKE CHOICES IF THEY SO WISH AND INDIVIDUALS WILL OF COURSE HAVE VERY DIFFERENT VIEWS ABOUT HOW AND WHETHER TO EXERCISE CHOICE.

THERE IS AN IMPORTANT THEME IN THE REFORMS ON RESTORATIVE CARE. THE IDEA THAT THE OLDER PERSON SHOULD BE SUPPORTED TO ACHIEVE THEIR MAXIMUM LEVEL OF INDEPENDENCE. WE HAVE YET TO FULLY UNDERSTAND HOW THAT SHOULD BE TRANSLATED INTO FINANCIAL INCENTIVES FOR RESIDENTIAL CARE PROVIDERS.

AND THERE IS A MUCH MORE OPEN DISCUSSION NOW THAN THERE WAS A DECADE AGO ABOUT END OF LIFE ISSUES, THE IMPORTANCE OF ADVANCE CARE DIRECTIVES THE NEED TO ENSURE THAT THE WISHES OF THE OLDER PERSON ARE RESPECTED.

WHILE WE MUST AIM FOR THE HIGHEST QUALITY OF LIFE OUTCOME IN RESIDENTIAL CARE IT IS IMPORTANT I THINK TO COME BACK TO THE POINT I MADE EARLIER ABOUT THE REALISM OF WHAT CAN BE ACHIEVED.

SOME OLDER PEOPLE ENTER RESIDENTIAL CARE BY CHOICE BECAUSE IT MAY GIVE THEM A GREATER SENSE OF SECURITY AND REDUCES THEIR SOCIAL ISOLATION.

OTHERS ENTER BECAUSE THERE IS LITTLE CHOICE IN TERMS OF THEIR OWN HEALTH OR LACK OF ACCESS TO INFORMAL CARERS WHO CAN SUPPORT HIGH CARE NEEDS.

OTHERS MAY ENTER RESIDENTIAL CARE RESENTFUL OF THE CIRCUMSTANCES WHICH HAVE LED THEM TO BE THERE.

AT ONE LEVEL THE ISSUES ARE PERHAPS OVERWHELMING IN NUMBER AND COMPLEXITY. AT ANOTHER LEVEL MANY OF THE THINGS THAT WILL MAKE A DIFFERENCE IN THE LIFE OF THE RESIDENT ARE EVERY DAY SMALL THINGS THAT MATTER – THE KIND WORD, ACCESS TO ACTIVITIES, MAKING THEIR FAMILIES WELCOME.

SOME WILL ARGUE THAT THE WORLD WILL NOT CHANGE WITHOUT GREATLY INCREASED RESOURCES. WE SUPPORT THE NEED INCREASED RESOURCES FOR DEMENTIA CARE BUT WE DO NOT BELIEVE IT IS THE ONLY ISSUE.

EQUALLY IMPORTANT IS THE CHANGE IN CULTURE THAT WILL RESULT IN GREATER RESPECT FOR THE DIGNITY AND RIGHTS OF THE OLDER PERSON AND THEIR FAMILIES.

IT SEEMS TO ME THAT THE APPROACH OF DOMAIN IS WELL AND TRULY ON THE RIGHT TRACK AND OVER THE YEARS WILL PAY DIVIDENDS BOTH IN THE QUALITY OF LIFE OF THE RESIDENT AND THE WORK SATISFACTION OF DOMAIN STAFF.

YOU DESERVE EVERY SUCCESS.