

**A NEW FUTURE FOR PEOPLE WITH YOUNGER ONSET DEMENTIA?
YOUNGER ONSET DEMENTIA SUMMIT**

MELBOURNE CONVENTION CENTRE

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THERE ARE MOMENTS IN A PERSON'S LIFE THAT ARE NEVER FORGOTTEN. I KNOW I SHALL NEVER FORGET THE STORY OF A WOMAN IN HER 50s, WITH YOUNGER ONSET DEMENTIA. SHE WAS SPEAKING AT A CONSUMER FORUM WE'D ORGANISED AT PARLIAMENT HOUSE, CANBERRA.

HER DIAGNOSIS OF YOUNGER ONSET DEMENTIA ROBBED HER OF HER CAREER AS A SCHOOLTEACHER. IT COMPLETELY CHANGED HER LIFE AS SUCH A DIAGNOSIS DOES.

"I FEEL DIMINISHED AS A PERSON AND DIMINISHED IN THE EYES OF MY SONS AS A MOTHER," SHE SAID.

THE DEPTH OF SADNESS WAS PAINFULLY EVIDENT. THIS MOTHER'S HEART FELT FOR HER....

YOUNGER ONSET DEMENTIA IS AN ILLNESS THAT MANY PEOPLE IN THE COMMUNITY ARE NOT AWARE OF; EVEN AMONG HEALTH PROFESSIONALS SUCH AS GPs, THERE IS A LACK OF AWARENESS, PROBABLY BECAUSE MANY HAVE NEVER DEALT WITH SUCH AN ILLNESS.

IT IS MY HOPE THAT DAY TWO OF OUR YOUNGER ONSET DEMENTIA SUMMIT WILL HELP TO PROMOTE A BETTER UNDERSTANDING OF THE COMPLEX ISSUES YOUNGER PEOPLE WITH DEMENTIA FACE.

I WANT TO THANK THE NATIONAL OFFICE OF ALZHEIMER'S AUSTRALIA AND ALZHEIMER'S AUSTRALIA VIC IN ORGANISING THE SUMMIT; THANKS ALSO TO NICH AND ROSEMARY RODGERS, THE LORD MAYOR'S CHARITABLE FOUNDATION AND THE COMMONWEALTH GOVERNMENT FOR THEIR FUNDING WHICH HAS MADE IT POSSIBLE.

DAY ONE OF THE SUMMIT YESTERDAY WAS A GREAT SUCCESS. WE ARE FORTUNATE TO HAVE PEOPLE WITH DEMENTIA AND FAMILY CARERS WHO ARE PREPARED TO SPEAK ABOUT THEIR OWN EXPERIENCES AND HOPES FOR IMPROVING SERVICES TO GET IMPROVED SUPPORT AND CARE. THESE HAVE BEEN DOCUMENTED IN A REPORT "YOUNGER ONSET DEMENTIA: A NEW HORIZON" WHICH I AM PLEASED TO BE LAUNCHING TODAY.

AMONG OTHER THINGS IT IS A REMINDER THAT THERE ARE MANY OTHER ISSUES TO ADDRESS INCLUDING EMPLOYMENT AND ACCESS TO INCOME SECURITY.

TODAY BRINGS TOGETHER CONSUMERS AND SERVICE PROVIDERS TO BETTER UNDERSTAND HOW WE CAN ENSURE WE PROVIDE THE SERVICES AND SUPPORT THAT PEOPLE WITH YOUNGER ONSET DEMENTIA ARE SEEKING SO THEY CAN ENJOY A GOOD QUALITY OF LIFE.

WE ARE AT A CROSSROADS IN THE FUNDING OF SERVICES FOR PEOPLE WITH DEMENTIA.

IN ITS RECENT REPORTS ON AGED CARE AND DISABILITY THE PRODUCTIVITY COMMISSION TOLD US WHAT MOST CONSUMERS ALREADY KNEW...AS A SOCIETY WE ARE FAILING TO PROVIDE SUPPORT AND SERVICES TO PEOPLE WITH DISABILITIES AND OLDER PEOPLE.

BOTH SYSTEMS ARE UNDERFUNDED, UNFAIR, FRAGMENTED AND INEFFICIENT; THEY PROVIDE LITTLE CHOICE OR CERTAINTY OF ACCESS TO APPROPRIATE SUPPORT.

HISTORIC CHANGES IN HEALTH POLICY ARE TAKING PLACE WITH THE ROLL OUT OF THE NATIONAL DISABILITY INSURANCE SCHEME (NDIS) AND THE FEDERAL GOVERNMENT'S AGED CARE REFORMS BUT THE EXCITEMENT OF THIS OPPORTUNITY FOR MAJOR SOCIAL REFORM TO BETTER ADDRESS THE NEEDS OF SOME OF THE MOST DISADVANTAGED PEOPLE IN OUR COMMUNITY IS SOMETIMES DROWNED OUT BY THE CONTINUING GLOBAL FINANCIAL CRISIS AND CONCERNS ABOUT BUDGET DEFICITS.

THE AGED CARE REFORMS AIM TO CREATE A SYSTEM WITH GREATER CHOICE AND FLEXIBILITY BUT THEY STOP SHORT OF THE ENTITLEMENT APPROACH RECOMMENDED BY THE PRODUCTIVITY COMMISSION. AGED CARE PLACES WILL CONTINUE TO BE RATIONED ON THE BASIS OF 127 PLACES PER 1000 PEOPLE AGED 70 PLUS, AND WITH ALLOCATIONS OF PLACES FOR RESIDENTIAL AND COMMUNITY CARE PACKAGES.

THE NDIS GOES FURTHER. IT PROMISES TO TRANSFORM A HEAVILY RATIONED SYSTEM INTO A MARKET IN WHICH FUNDING IS ALLOCATED TO THE PERSON WITH THE DISABILITY AND THEIR FAMILIES SO THEY WILL BE ABLE TO EXERCISE CHOICE OVER THE SERVICES THEY RECEIVE. YOUNGER PEOPLE WITH DEMENTIA WILL BE ELIGIBLE FOR ASSISTANCE UNDER THE NDIS.

SO IT IS IMPORTANT WE UNDERSTAND THE NDIS AND HOW WE CAN PROMOTE A BETTER UNDERSTANDING OF THE NEEDS OF YOUNGER PEOPLE WITH DEMENTIA.

THE NATIONAL DISABILITIES INSURANCE SCHEME REFLECTS A PHILOSOPHY AND APPROACH I THINK WE WOULD ALL SUPPORT.

AT THE CORE OF THE NDIS ARE FOUR PRINCIPLES:

- **A LIFETIME APPROACH IN WHICH FUNDING IS LONG TERM AND SUSTAINABLE. INDIVIDUALISED CARE AND SUPPORT WILL BE FLEXIBLE AND ABLE TO CHANGE IN RESPONSE TO CHANGES IN INDIVIDUAL GOALS OR CARE NEEDS.**

- **CHOICE AND CONTROL ENABLING PEOPLE TO CHOOSE HOW THEY GET SUPPORT AND TO HAVE CONTROL OVER WHEN, WHERE AND HOW THEY RECEIVE IT. FOR SOME THERE MAY BE THE POTENTIAL TO MANAGE THEIR OWN FUNDING.**
- **SOCIAL AND ECONOMIC PARTICIPATION SO THAT PEOPLE WITH A DISABILITY HAVE THE SUPPORT TO LIVE A MEANINGFUL LIFE IN THEIR COMMUNITY AND THUS ACHIEVE THEIR FULL POTENTIAL.**
- **FOCUS ON EARLY INTERVENTION WITH AN INVESTMENT IN EARLY INTERVENTION TO HELP PEOPLE TO PURSUE THEIR GOALS AND MITIGATE, ALLEVIATE OR PREVENT THE DETERIORATION OF THEIR FUNCTIONAL CAPACITY.**

HOW THIS TRANSLATES INTO INDIVIDUAL SERVICE PLANS WILL DEPEND ON THE FURTHER DESIGN AND DEVELOPMENT OF THE SCHEME. CLEARLY THERE ALWAYS WILL BE LIMITS TO THE AMOUNT OF ASSISTANCE AVAILABLE.

THERE WILL ALSO BE MULTIPLE INTERFACES BETWEEN THE NDIS AND THE HEALTH AND AGED CARE SYSTEMS, PARTICULARLY IN TERMS OF DIAGNOSIS, ASSESSMENT AND SERVICES. THEREFORE, THE RULES THAT WILL GOVERN THE SCHEME WILL BE COMPLEX.

THE LEGISLATION TO IMPLEMENT THE NATIONAL DISABILITIES INSURANCE SCHEME IS BEFORE PARLIAMENT.

THE LAUNCH OF NDIS IS DUE TO OFFICIALLY START IN FIVE LAUNCH AREAS AROUND AUSTRALIA FROM 1 JULY 2013. THEY WILL BE IN SOUTH AUSTRALIA, TASMANIA, THE ACT, THE HUNTER REGION IN NSW AND THE BARWON SOUTH WEST AREA OF VICTORIA.

THE SITES IN THE BARWON AND HUNTER REGIONS ARE PERHAPS MOST RELEVANT TO TESTING THE ELIGIBILITY OF PEOPLE WITH YOUNGER ONSET DEMENTIA AND THE SUPPORT THEY MIGHT ATTRACT.

THE CHALLENGE FOR ALZHEIMER'S AUSTRALIA AND OUR CONSUMER STAKEHOLDERS NOW IS TO ENSURE THE NEEDS OF PEOPLE WITH YOUNGER ONSET DEMENTIA ARE ARTICULATED IN A WAY THAT'S UNDERSTOOD BY THE NDIS AGENCY AND SERVICE PROVIDERS.

AND THAT IS WHAT A LARGE PART OF THIS SUMMIT WAS DEVOTED TO YESTERDAY.

THE NDIS AND THE AGED CARE REFORMS WILL BRING WITH THEM CHALLENGES FOR ALL THE STAKEHOLDERS – GOVERNMENT, SERVICE PROVIDERS AND CONSUMERS.

A CHANGE IN ATTITUDES WILL BE ESSENTIAL. FOR INSTANCE...

- **THE GOVERNMENT WILL NEED TO BE LESS REGULATORY AND RISK ADVERSE.**
- **SERVICE PROVIDERS WILL NEED TO BE MORE CREATIVE AND RESPONSIVE IN THE WAY THAT THEY MEET THE PREFERENCES OF CONSUMERS.**

- **CONSUMERS WILL HAVE TO BE BETTER INFORMED AND PREPARED TO MAKE CHOICES ABOUT THE SORTS OF SERVICES THEY RECEIVE AS WELL AS THE PROVIDERS THEY RECEIVE THEM FROM.**
- **THE COMMUNITY WILL NEED TO BE LESS RISK ADVERSE AND LET YOUNGER AND OLDER PEOPLE MAKE CHOICES.**

A RANGE OF CHALLENGING ISSUES HAS BEEN IDENTIFIED BY CONSUMERS IN RESPECT OF SERVICES AND THIS STARTS WITH ASSESSMENT.

WE KNOW THAT ON AVERAGE FROM THE SIGNS OF FIRST DIAGNOSIS IT TAKES THREE YEARS FOR A PERSON TO OBTAIN A DIAGNOSIS OF DEMENTIA. PEOPLE WITH YOUNGER ONSET DEMENTIA FACE AN EVEN LONGER DELAY SIMPLY BECAUSE MEDICAL PROFESSIONALS ARE NOT EXPECTING TO FIND DEMENTIA AMONG YOUNGER PEOPLE.

THIS DELAY RESULTS IN LOST YEARS SPENT WONDERING WHAT IS WRONG RATHER THAN HAVING ACCESS TO MUCH NEEDED SERVICES AND SUPPORTS.

FOR MOST PEOPLE WITH YOUNGER ONSET DEMENTIA, DIAGNOSIS OF THE DISEASE IS A LONG, EXPENSIVE AND FRUSTRATING PROCESS THAT CAN VARIOUSLY RELY ON THE INVOLVEMENT OF GPs, NEUROLOGISTS, GERIATRICIANS, PSYCHOLOGIST, NEUROPSYCHOLOGISTS , OCCUPATIONAL THERAPISTS AND SOCIAL WORKERS, NOT TO MENTION AGED CARE ASSESSMENT TEAMS. NO WONDER PEOPLE GET CONFUSED!

WHEN THE DIAGNOSIS OF YOUNGER ONSET DEMENTIA IS FINALLY OBTAINED HOWEVER, INDIVIDUALS AND THEIR FAMILY CARERS ARE INVARIABLY FACED WITH A LACK OF ACCESS TO AGE APPROPRIATE SERVICES.

IT REMAINS THE CASE EVEN IN THE AGED CARE SYSTEM THAT ACCESSING APPROPRIATE SERVICES, PARTICULARLY RESPITE CARE, IS DIFFICULT FOR PEOPLE WITH YOUNGER ONSET DEMENTIA.

THIS IS OF PARTICULAR IMPORTANCE WHEN CONSIDERING THE NDIS. ALTHOUGH A MARKET-BASED APPROACH TO SERVICES WILL PROVIDE NEW OPPORTUNITIES FOR CONTROL AND CHOICE – WHAT WILL BE THE REALITY FOR PEOPLE WITH YOUNGER ONSET DEMENTIA? WILL THERE BE APPROPRIATE SERVICES AVAILABLE FOR THEM TO CHOOSE FROM?

THE INEVITABLE CONSEQUENCE OF LIMITED AGE APPROPRIATE COMMUNITY CARE SERVICES IS INSTITUTIONAL CARE.

ACCORDING TO RECENT DATA OBTAINED BY ALZHEIMER'S AUSTRALIA FROM THE DEPARTMENT OF HEALTH AND AGEING, OF THE 6169 PEOPLE UNDER THE AGE OF 65 IN RESIDENTIAL CARE, AROUND 31 PER CENT (THAT IS ALMOST 2000), HAVE A DIAGNOSIS OF DEMENTIA. THE VAST MAJORITY ARE IN HIGH CARE.

TODAY'S SUMMIT HAS BEEN SPECIFICALLY DESIGNED TO BRING PEOPLE WITH DEMENTIA AND THEIR FAMILY CARERS TOGETHER WITH SERVICE PROVIDERS TO LISTEN, SHARE AND DEVELOP VIEWS ABOUT HOW TO DEVELOP SERVICES THAT RESPOND FLEXIBLY TO THE GOALS AND NEEDS OF YOUNGER PEOPLE WITH DEMENTIA.

IT IS ONE THING TO ESTABLISH A FRAMEWORK WITHIN WHICH FUNDING WILL BE PROVIDED AND ANOTHER TO ACHIEVE A SUPPLY SIDE RESPONSE THAT PROVIDES THE SUPPORT AN INDIVIDUAL NEEDS.

WITHIN THE HIGHLY REGULATED AGED CARE SECTOR, IT HAS BEEN DIFFICULT TO ACHIEVE FLEXIBLE SERVICE RESPONSES. THE DESIGN OF THE NDIS AND OF THE ADOPTION OF THE CONSUMER-DIRECTED CARE MODEL IN AGED CARE PROVIDES AN OPPORTUNITY FOR PARTNERSHIP BETWEEN CONSUMERS AND SERVICE PROVIDERS.

FOR THE FIRST TIME, YOUNGER ONSET DEMENTIA HAS BEEN RECOGNISED IN NATIONAL HEALTH AND AGED CARE POLICY IN THE *LIVING LONGER. LIVING BETTER.* PACKAGE. SIXTEEN MILLION DOLLARS HAS BEEN PROVIDED OVER FOUR YEARS FOR YOUNGER ONSET DEMENTIA KEY WORKERS.

ALZHEIMER'S AUSTRALIA HAS BEEN GIVEN RESPONSIBILITY FOR THIS FUNDING AND TO EMPLOY 40 KEY WORKERS AUSTRALIA WIDE TO IMPROVE THE SUPPORT AND SERVICES AVAILABLE TO PEOPLE WITH YOUNGER ONSET DEMENTIA.

**FOR MANY YEARS PEOPLE OF ALL AGES WITH DEMENTIA HAVE
ADVOCATED FOR KEY WORKERS WHO WOULD PROVIDE THE ONGOING
LINK TO WHAT IS UNDENIABLY A COMPLEX AND CONFUSING CARE
SYSTEM – EVEN FOR THOSE WITH A HEALTH OR AGED CARE
BACKGROUND.**

**SO THE FUNDING OF THESE KEY WORKERS REPRESENTS A SIGNIFICANT
STEP FORWARD BY GOVERNMENT IN RESPONDING TO THE ADVOCACY OF
CONSUMERS.**

**THESE KEY WORKERS WILL IDENTIFY SERVICE GAPS, INSIST ON SERVICE
DEVELOPMENT AND PROVIDE INDIVIDUALISED SUPPORT TO ASSIST
INDIVIDUALS TO ACCESS THE CARE AND SUPPORT THEY NEED.**

**BY THE MIDDLE OF THIS YEAR, THE KEY WORKERS WILL BE IN PLACE AND
UNDERTAKING THEIR ROLES. CLEARLY THEY WILL PLAY AN IMPORTANT
ROLE IN ASSISTING YOUNGER PEOPLE WITH DEMENTIA AND THEIR
FAMILIES TO GET ACCESS TO THE NDIS AND TO UNDERSTAND THE
CHOICES AND SERVICES THAT ARE AVAILABLE TO THEM.**

THERE ARE CRUCIAL QUESTIONS TO ADDRESS IN THE CONTEXT OF THINKING ABOUT INDIVIDUALISED SERVICE PLANS IN THE NDIS.

WHAT KIND OF SERVICES SHOULD CONTINUE TO BE BLOCK- FUNDED TO ENSURE EFFICIENCY OF DELIVERY OF HIGH VOLUME SERVICES SUCH AS INFORMATION AND COUNSELLING?

WHILE THE OBJECTIVE IS TO REDUCE REGULATION, HOW CAN RISKS BE MANAGED APPROPRIATELY IN TERMS OF INDIVIDUAL PARTICIPANTS, SERVICES, COSTS AND MARKET READINESS?

HOW CAN WE ENSURE THAT ASSESSORS ARE FAMILIAR WITH DEMENTIA... AND HOW WILL EARLY INTERVENTION WORK FOR PEOPLE WITH YOUNGER ONSET DEMENTIA.

WE WILL ONLY FIND ANSWERS TO THESE AND OTHER QUESTIONS IF THERE IS A STRONG PARTNERSHIP BETWEEN CONSUMERS AND SERVICE PROVIDERS IN WORKING THROUGH HOW FLEXIBLE SERVICE RESPONSES CAN BE ACHIEVED. THIS SUMMIT IS AN IMPORTANT STARTING POINT FOR THAT PARTNERSHIP APPROACH.

IF IMPLEMENTED WELL THE NDIS WILL BE THE MOST IMPORTANT AND AMBITIOUS REFORM OF THE DISABILITY SERVICES SYSTEM IN A GENERATION.

WE MUST MAKE SURE IT DELIVERS FOR PEOPLE WITH YOUNGER ONSET DEMENTIA.

THANK YOU