

An Australian Government Initiative



## Rights of People with Dementia and Advocacy Project

Assisting people with dementia to maintain decision making control over their lives



An initiative of Advocacy Tasmania Incorporated  
In partnership with Alzheimer's Australia Tasmania

An Australian Government funded project helping Australians with dementia & their carers

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Ken Hardaker – CEO Advocacy Tasmania

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## Executive Summary

Advocacy Tasmania Incorporated (ATI) in partnership with Alzheimer's Australia Tasmania developed an innovative early intervention project targeting people recently diagnosed or in the early stages of dementia who live alone/without positive supports in their lives. The *Rights of People with Dementia and Advocacy Project* was highly successful in meeting its aims and objectives and filling an unmet need. All the project aims and objectives directly relating to clients were met; and a range of barriers to client's voice in transitions was identified. Significant education of stakeholders occurred and ongoing networks have been developed to assist people living with dementia into the future.

Many elderly people experience great stress and difficulty with the onset and progression of dementia but are invisible until a crisis. This may result in premature entry to residential care, financial and emotional abuse; and isolation from family and community. As advocacy models are issues-based, the reliance on referrals being made by the person or someone closely associated with them favours more intellectually capable older persons or those with active family members. People living with dementia who live alone are under-represented and experience multiple disadvantages.

The model of advocacy used by *the Rights of People with Dementia and Advocacy Project* includes ongoing contact with the person living with dementia and a proactive and preventative perspective to as much as possible, avoid problems occurring. Professional advocates operated as 'enabling guides' in futures planning and through the care system providing information, support and advocacy when needed. Through focusing on early identification and enabling support the project empowered people with dementia to articulate their preferred future, establish their wishes, make financial plans, strengthen the environment around them; and reduce their vulnerability to abuse. In addition the project facilitated:

- Ongoing support and issues based advocacy at all stages of the dementia spectrum
- Development of pathways and smooth transition with service providers
- Education of stakeholders regarding rights of people with dementia.

Through an action research/learning methodology overseen by a Reference Group of major stakeholders from Advocacy Tasmania, Alzheimer's Australia Tasmania, The Division of General Practitioners South, Migrant Resource Centre, GAB, ACAT, the state government HACC program; and Aged Care providers; the project framework promoted a continuous improvement cycle where the Reference Group was both advisor to the project and recipients of learning as it unfolded.

The independent evaluation component including client interviews, family interviews, a service provider questionnaire; and interviews with the CEOs of the partner organizations resulted in further evidence of the project's success and demonstrated its empowering potential for people living with dementia who live alone.

Overwhelmingly the feedback from the project was positive with some clients indicating it was life-changing in its support. All 79 of the people who used the project gained some benefits. More personalised plans (for now and the future), reconnecting with family and significant others and extending time to live at home were dominant themes. For a number of clients the planning and support offered via the project was an effective strategy in preventing or managing abuse, particularly financial abuse.

Clients and families valued the independence of the advocate and saw trustworthiness/independence as an essential element of developing plans for the future. Significantly, clients and family members also commented on learning from the Project Advocate's approach to advocating and resolving problems.

The project successfully informed 350+ people about the project, its rationale and aims; and of the rights of people living with dementia. Service providers reported they gained more understanding of the rights of people in the target group, extended their understanding of advocacy; and improved their capacity to both identify people living with dementia who live alone and make appropriate referrals.

The project found that:

- Access to help, advice and supports as early as possible improves the quality of life for the person living with dementia, appears to slow the disabling impact of dementia (through reduced stress, solved problems and better health care management); and delays the need to enter residential care.
- People living with dementia are able to participate in planning and decision-making about many aspects of their life when they have access to appropriate information and support. They value their right to retain some control over their lives and want to preserve a sense of self-determination.
- The critical features/characteristics of the project advocacy approach are:
  - Person centred approach
  - Maximising independence and building on strengths
  - Focus on decision making and control
  - Planning as a strategy
  - Effective communication
  - The independence of the advocate.
- People living with dementia who are alone may have 'lost' connection with family and community but reconnection can be facilitated surprisingly easily with positive impact on quality of life.
- Many barriers to the voice of people living with dementia are societal factors rather than related to the person's condition of dementia.
- Having support from the Project Advocate increased the credibility of people living with dementia and their opinions by strengthening their voice and giving an additional voice. The presence of an advocate has an educative effect in sending a message about recognizing the person has rights.

The project team makes a range of recommendations to the health and aged care sector that includes providing access to independent dementia-specific advocacy services, promoting a stronger consumer rights focus and meaningful consumer participation within services, emphasising person-centred holistic approaches consistent with emerging discourse in community care around well-being, wellness and capacity building; and assessing and responding to issues of social isolation with focussed efforts to connect people living with dementia who live alone in the community with someone.

The team considers there are 9 implications for aged care policies and programs:

1. More policy focus on people living with dementia who are alone and without supports:
2. Requiring services to evidence consumer input into decision-making and planning as a quality element of accreditation
3. Maintaining and sustaining the policy position around wellness and capacity:
4. The Federal government to assume a more active role in policy development for prevention and response to community-based Elder Abuse
5. Policy development that is consistent with the wellness model in promoting acceptance of the community sector's role in overcoming social isolation
6. Public Awareness campaign that presents a positive image of people living with dementia and affirms their rights continue to make decisions about their life
7. Recognise via policy and programs the potential importance of advocates' contributions in supporting this client group in the community
8. Strategy to encourage all adults to make advanced directives for future lifestyle and financial options such as Wills, Enduring Power of Attorneys, Guardianship and Advanced Medical Directives
9. Development of standardized approaches to assessment of decision-making capacity.

The potential of the project for broader application is recognized in Home and Community Care providing funding to enable the project to continue until the end of 2008 and examining potential to extend it across Tasmania.

## The Project's Aims and Objectives

1. Proactive and preventative support to clients recently diagnosed with dementia
  - i. Provide clients with information and advice to enable them to plan for the future.*
  - ii. Act as an enabling guide for clients to manage transitions between service providers.*
  
2. Ongoing support and issues based advocacy at all stages of the dementia spectrum
  - i. Advocate for clients on issues and problems of concern to them.*
  
3. Systemic development of pathways and smooth transition with service providers
  - i. Identify barriers to client's voice being heard in transitions and assessment processes and document examples of good practice.*
  
4. Education of stakeholders regarding rights of people with dementia
  - i. Provide education to stakeholders regarding the rights of people with dementia.*
  - ii. Document improvements in the aged care sector which promote the rights of people with dementia.*

## The Project Methodology

### People Living With Dementia and Access to Advocacy Services

Historically advocacy services for older Australians, including people with dementia, are funded by Governments, state and commonwealth<sup>1</sup>, to assist people who have a complaint or concern regarding an aged care or community care service. The model of advocacy is “issue-based”, that is, an advocate is provided to assist the older person (or family member) until their issue is resolved. The issues that advocates pursue on behalf of their clients are predominantly related to quality of care and service delivery. While this model of advocacy is very successful, it is a reactive approach, endeavouring to remedy problems after they occur. The process relies on referrals being made to the service by the older person or someone closely associated with them; and favours more intellectually capable older persons or those with active and interested family members.

People with moderate to advanced dementia find it difficult to access issue-based advocacy services. Generally referrals from people in this group are received from a family member who relates to and directs the advocate. Consequently people living with dementia who live alone are at high risk of multiple disadvantages in accessing issues-based advocacy model services.

### The Advocacy Model of the Project

The model of advocacy used by *the Rights of People with Dementia and Advocacy Project* takes a different tact to issues-based advocacy - one which includes ongoing contact with the person living with dementia and a proactive and preventative perspective in order to, as much as possible, avoid problems occurring.

The key to the model is referral to the advocate of a person in the early stages of dementia. The advocate establishes a relationship with their client, builds a rapport and an understanding of their priorities and hopes for the future while the person still has the capacity to communicate and reason. For those who wish to put in place formal mechanisms to assist them to manage their lives as the dementia progresses this can be done; and includes Enduring Powers of Attorney, Enduring Guardianship, Advanced Medical Directions and Will Making. For many people future plans are more about maintaining valued relationships and activities. As trust builds between advocate and client, the advocate can raise a range of issues the client may wish to consider, including accessing care services. But it is the client who sets the agenda and makes the decisions. As problems emerge confronting the person living with dementia the advocate is available to assist them to analyse the problem, to consider the options for resolving it, and to provide advocacy to address it once the client has decided on the course of action they wish to take. The advocate is therefore a tool to assist the person living with dementia to manage their life as their dementia progresses.

The model postulates the concept of a continuum of advocacy involvement. As the person's dementia progresses the advocate is likely to be called on to take a more active role. This includes supporting the person with increasing contact with the health system i.e. doctors' visits, aged care assessments, dealing with care providers. However, in all instances the

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<sup>1</sup> The National Aged Care Advocacy Program funds independent advocacy services in each state and territory to assist people in receipt of Commonwealth funded aged care services both residential and community care. The Home And Community Care (HACC) programs in most States provide funding to the same organisations for advocacy to people using HACC services.

advocate's role is to assist the person to communicate their wishes and help the person to process the information they receive in order to continue making decisions about their life.

Ultimately, many people living with dementia will be admitted to residential care. For those linked with a dementia rights advocate, the client/advocate relationship continues. The advocate maintains contact with the person, visits periodically, advocates on their behalf where necessary - keeping a constant eye out for their rights and interests. As they know the person well when they are still intellectually competent they have, in essence, prior instructions from their client as to their needs, wishes, likes, and dislikes. By this means even people who are profoundly disabled by their dementia can have their rights protected and their voice heard via their advocate.

In Australia the emphasis on service delivery for people with dementia living in the community has also tended to be about provision of care services - in keeping people safe and physically well cared for, often with a focus on supporting their carer - if they have one. It has been about looking after the body of the person. *The Rights of People with Dementia and Advocacy Project*, in contrast, concentrates on assisting the person's mind, in aiding mental functioning through support in decision-making. This style of advocacy support has the added benefit of reducing stress on the individual by assisting them to deal with a wide range of problems that present as their dementia progresses.

## **Project Method**

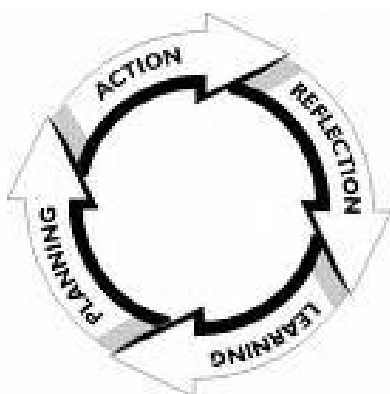
The *Rights of People with Dementia and Advocacy Project* employs one full-time Project Advocate with responsibility for:

1. Proactive and preventative support to clients recently diagnosed with dementia
2. Ongoing support and issues based advocacy at all stages of the dementia spectrum
3. Development of pathways and smooth transition with service providers including feedback regarding best practice and promising practice
4. Education of stakeholders regarding rights of people with dementia.

People in the early stages of dementia who live on their own and have no carer/family or limited contact with family are the intended recipients of the service.

The Project Advocate works with key contacts such as Alzheimer's Australia Tasmania, general practitioners, geriatricians, hospitals, ACAT teams, HACC services, Carelink, Commonwealth Carer Respite Centres, Public Trustee and Public Guardian, to encourage potential clients to contact the project as early as possible after their diagnosis of dementia. The Project Advocate follows up referrals, meets with the client at a time and place of their choosing; and develops a trusting ongoing relationship. This quality relationship provides the foundation for the Project Advocate to become an 'enabling guide' through the care system, providing information and support; and acting as their advocate when needed.

A Reference Group consisting of representatives from Advocacy Tasmania Incorporated, Alzheimer's Australia Tasmania, The Division of General Practitioners South, Migrant Resource Centre, GAB, ACAT, the state government HACC program; and Aged Care providers guided the project via an Action Research/Action Learning model.



This active involvement of stakeholders aimed to identify factors that negatively impact on people with dementia's rights / experience of service delivery, generate positive solutions; and establish a cycle for continuous improvement in service delivery.

Figure 1: Action Research/Action Learning Model

### Independent Evaluation – Purpose and Method

The independent evaluation provides evidence of the pilot project's effectiveness and how far the aims have been achieved. Specifically it planned to:

- Gather evidence on the significance of the project from primary users, families and service providers
- Offer evidence-based comment on key characteristics that promote positive benefit
- Explore the impact of the project on the network of local services for people living with dementia and their families.

The evaluation method consisted of interviewing, questionnaires and documentary analysis of subjects raised in the context of the Reference Group. Data was analysed and coded thematically. In total 31 people expressed their opinions of the *Rights of People with Dementia and Advocacy Project*.

<b>Clients</b>	A representative group of 9 clients ( $\sqrt{79}$ rounded up) Chosen via random and convenience sampling Interviewed face-to-face at a place of their choosing Average length of interview 1 1/2 hrs
<b>Family/partners</b>	A representative group of 7 ( $\sqrt{44}$ rounded up) 3 interstate or overseas (sons/step daughter) 1 local limited contact (brother) 1 local active involvement (brother) 2 partners (wives)  Chosen randomly - included some who were experiencing verbal or financial abuse from other family members  Interviewed face-to-face (4); via phone (3)  Duration of interview varied from 3/4hr to 1 1/4 hrs
<b>Service providers</b>	A web-based questionnaire for service providers (n=13) In depth interview with the CEOs of the partner organisations (n=2)

A synopsis from the evaluator is included within relevant sections of this report.

## Statement - whether the Project's aims and objectives were met

*Jim, 84 is fiercely independent, resourceful and living alone. A 90 year old brother is his only relative in Australia. Jim was introduced to the Project Advocate by a CALD community worker. Jim's GP and the CALD worker had discussed seeking permanent residential care - Jim was vehemently opposed to this. In addition to mild to moderate dementia, the GP had diagnosed Jim with gastric and rheumatic conditions requiring treatment. As he has a strong belief in alternate medicine and mistrusts most doctors, Jim refused proposed treatment including hospitalization. Following several meetings/chats with the advocate, Jim acknowledged his level of pain and requested the endoscope procedure previously recommended by his GP. The success of the treatment following the procedure built Jim's confidence in both the Project Advocate and his GP. Jim acknowledged his need for support services however this raised occupational health and safety issues for workers relating to Jim's physical environment. The Project Advocate supported Jim through the necessary actions to enable services to commence.*

*Over time Jim's needs continue to change and his desire for appropriate assistance has increased. To date this has included:*

- Medication for his rheumatic condition*
- Referral to a psycho geriatrician to investigate his memory loss*
- The introduction of a level of in-home support that pleased and suited Jim*
- An ACAT assessment and support during the process*
- A referral to AAT Living With Memory Loss program*
- Assistance to access social activities*
- An increase in his level of in-home support*
- The advocate to attend medical and significant appointments with him.*

*Jim continues to make decisions about his life and to live at home....*

While the Project had only one year to demonstrate the effectiveness of the advocacy model we believe it did do so convincingly.

All the project aims and objectives directly relating to clients were met; and a range of barriers to client's voice in transitions was identified. Significant education of stakeholders has occurred and will continue as part of the reporting process.

All 79 of the people who used the project gained some benefits. In some cases these were one-off benefits involving limited contact with the Project Advocate e.g. to assist them to draft a power of attorney or advanced medical directive. In other cases there were multiple benefits achieved over a more extended period and involving many contacts with the Project Advocate.

*Mary is a retired professional who travelled extensively prior to arriving in Tasmania 4 years ago. Her local friendship network was not established before the onset of dementia. At 75 Mary lived alone with mild/moderate dementia and fairly complex physical health issues in a picturesque apartment with a complex security access system. Her children lived interstate or overseas and were concerned about her. Initially they perceived that she denied her dementia - they felt it was increasing significantly. Following several incidents when Mary was unable to get into her apartment, the body corporate and neighbours challenged Mary's ability to remain living independently within the apartment setting. Mary asked the Project Advocate to liaise with the body corporate and explore options to assist her in living safely in her home. This was successful and strategies were put in place.*

*Other needs which arose and were addressed for Mary included:*

- support to organize household tasks, shopping*
- support with medical appointments*
- joining the Living with Memory Loss program*
- ACAT assessment for a CACP.*

*Things were going well for some months; however eventually there was a decline in her dementia, which included experiencing hallucinations. The Project Advocate liaised with Mary's GP to organize a referral to a psycho geriatrician who recommended Mary's family to be informed of the changes. Mary agreed. The Project Advocate liaised with family, service providers and ACAT to increase services. Mary's son visited and spent considerable time gaining information about the dementia process, the aged care system, Mary's rights, needs and future wishes. He organized the application processes, discussed options and alternate decision making arrangements with overseas family members. Everyone worked towards a successful transition for Mary into a residential care facility that would meet her changing needs and ensure an ongoing connection with her family.*

These case studies demonstrate the value an independent advocate brings to situations often confronting a person with dementia; and are typical of many of the project's activities during the pilot phase.

The key characteristics of these case studies are:

- Early linking with the advocate which is particularly important for clients who live alone and do not have well developed local support networks
- Advocate established rapport and trust while the client was still functioning intellectually at a fairly sophisticated level
- Advocate assisted clients to introduce formal support services for the first time
- Client took other steps to better manage their dementia e.g. joining the Living with Memory Loss Group; requesting the advocate support them with critical medical appointments and assessments
- Advocate assisted them to solve other problematic situations e.g. negotiating with body corporate; assisting to resolve the 'clean up' issue that was impeding the possibility of formal support services being introduced
- When client started to deteriorate the advocate was a bridge to supportive family members which avoided the need for a more formal substitute decision-making process i.e. emergency guardianship hearing
- The transition to residential care was managed in a manner that caused the client the least stress.

## Evaluator's Comments

### Client Perspective

100% of clients interviewed describe the assistance provided via the project positively and believe it should be available to others with dementia or memory loss. Their rationale for its usefulness reflects the client-centred strands of the project i.e. targeted information, planning and advocacy using proactive, preventative approaches.

"Absolutely, jingo yes! I know Project Advocate helped someone who was on the verge of suicide..."

"Certainly - especially when you are on your own and have moved states too! More than useful - it could be a life saver... it is part of the essentials"

"Definitely - hell yeah! You get contacts and people take a personal interest in you.. making sure you are alright..."

"An advocate is a good thing! I'm glad the government is helping older people particularly (if they are) bereft of family... Good (to have a Project Advocate who is proactive) because people are hard to get on the phone - they ring you back and you can't remember what you needed to talk with them about."

### Family Perspective

100% of families interviewed are positive about the project. Common themes include:

- ✓ The 'trustworthiness' of the Project Advocate
- ✓ Someone 'on the ground who knows what's was going on'
- ✓ Better access to services
- ✓ Strategies to improve the safety and security for their family member
- ✓ Addressing abuse issues; and
- ✓ Helping the family reconnect and get positively involved.

Several family members believed that their family member with dementia was able to live at home longer as a direct result of the project.

### Service Provider Perspective

Of the 13 service providers who responded to the questionnaire, 12 strongly believed there was an ongoing need for the type of support provided by the project. All identified significant strengths with the project that reflected its intentions and validated the anticipated outcomes of the project.

"Independent support and assistance to those who are vulnerable - no conflict of interest"

"Information, advice, support on enduring power of attorney and guardianship – invaluable!"

"Huge potential assisting in navigating the maze of community services"

"Advocate builds a good relationship with the client and then works with service providers to ensure appropriate support is in place"

"Number of people living with dementia who access support and advocacy has increased"

"Offers people with memory loss a strong voice in the community"

"Great potential for education, training and link with General Practitioners"

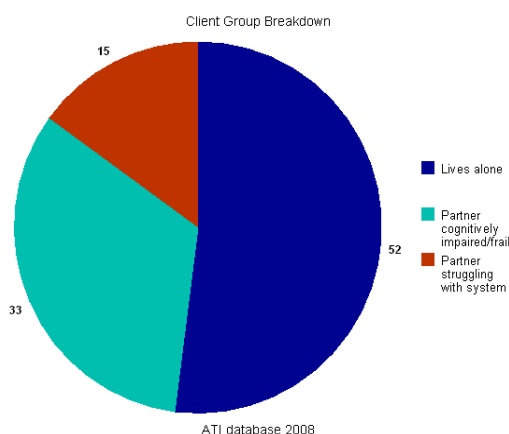
"Two out of three, of which I was aware, were enabled to stay at home much longer"

"All the referrals we made to the service resulted in excellent outcomes for the client."

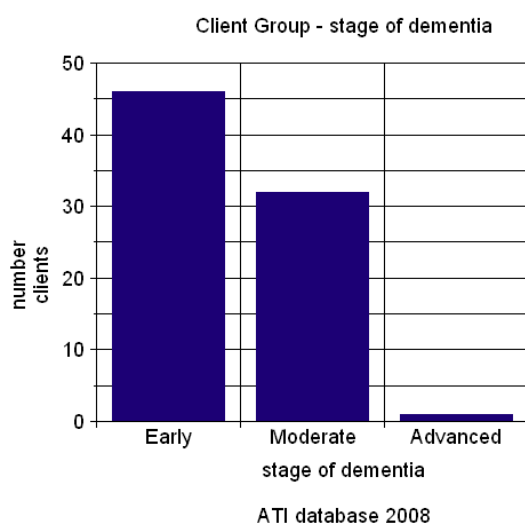
## The Outcomes of the Project

### 1. Proactive and preventative support to clients recently diagnosed with dementia

*Magda values the Project Advocate initiating contact and not assuming everything is all right. She says it is too hard to say, "I need someone to prop me up", but strongly believes it "takes more than one person to get it right". Magda was feeling pessimistic about planning for the future but found the project valuable because "it draws you into the care, gets you interested". She feels a lot of people don't get a chance to talk. (Evaluation Interview)*



During the life of the project 79 people living with dementia received assistance from the Project Advocate. Of the 79 people, 67 were in vulnerable or precarious circumstances of isolation/aloneness - 41 living alone, 26 with partners who were also cognitively impaired and/or frail. The remaining 12 had some support but their partners were struggling to navigate the service system.



The project was well targetted to those in the early stages of dementia with 46 of the 79 clients recently diagnosed or in the early stages of dementia. As the project also hypothesized around client support issues during transition, some clients with moderate dementia (32) and 1 with advanced dementia were included to see if the project process was beneficial.

**i. Provide clients with information and advice to enable them to plan for the future.**

*Ada a retired psychologist referred herself to the project following an information session at her local Seniors Action Group. She is 76, single, has no family; and recently moved to Tasmania for health and lifestyle reasons. Ada became aware of gaps in her futures planning. Over several months the advocate supported Ada to consider her options for appointing an Enduring Guardian and assisted with the preparation of Advanced Medical Directives. Ada also requested information about aspects of the aged care system.*

**Outputs: Planning**

Information provided to clients included:

- List kits, information sheets – see appendix A
- Advanced Medical Directives (11 clients)
- Enduring Power of Attorney (28 clients)
- Enduring Guardianship (10 clients)
- Information about services, referrals, assessment processes (40 clients)

Sixty-six clients (84%) decided to make plans about the future. These included formal mechanisms to assist them to manage their lives as the dementia progresses; and future plans around quality of life, maintaining valued relationships and lifestyle.

**Formal Advanced Directives**

- 28 clients supported to establish EPOA
- 10 clients supported to prepare Enduring Guardianships
- 11 clients assisted to prepare Advanced Medical Directives
- 7 clients assisted to locate access or change their Will.

**Lifestyle/Quality of Life Plans**

- 5 people supported to identify their desire to regain lost contact with family and friends interstate and overseas
- 5 people assisted to achieve reconnection with family and friends
- 9 people assisted to regain contact with social or interest groups to which they had previously belonged
- 10 people (including 3 carers) referred to 'Living with Memory Loss Program', Alzheimer's Australia Tasmania
- 22 linked/referred to other services
- 2 people assisted to access alternative community accommodation

*At 82 Bob is physically fit and lives alone. His son, Keith lives interstate and phones infrequently. Bob always reports everything is fine – Keith is unaware of his father’s dementia. Bob is experiencing difficulty managing payment of accounts, personal hygiene and attending to household tasks. Increasingly his diet is becoming limited. As the relationship between the Project Advocate and Bob grows, he identifies problems with his memory but demonstrates how much he is able to control aspects of his life. The Project Advocate reinforces Bob’s strengths and desire to be independent while exploring future lifestyle and service options to fulfil his goal. Bob likes the idea of some delivered meals... The success of this gains Bob’s confidence and he participates in research to re-contact Keith. Contact was made and Bob now lives in accommodation 15 minutes from Keith. He says it is nice and quiet, with privacy and his own space but opportunity to mix with others - just how he likes it.*

### **Outcomes - Planning**

“I’m amazed at the extent I hadn’t thought of things and details... You can specify what you want and don’t want... I had no idea. I let my friend (interstate) know about it all... there is no help (like this) where he is. I’d made provisions for Power of Attorney but hadn’t realised Guardianship was separate because there are variations across the states... When life is becoming more restricted each element of your actions is more important than before...”  
(Client – Evaluation Interview)

The project clearly demonstrates the desire of many people living with dementia to plan for the future and the value they place on planning during the early stages of dementia. Some clients expressed a desire to explore future options and decision making prior to meeting the advocate. In general these people are in the very early stages of the dementia process. Other clients do not readily identify possible opportunities or the need to make plans for their future support or other needs. They may express awareness of some memory loss but have no knowledge of the progress or outcome of dementia. Consequently discussions about the future must be handled with great sensitivity to avoid causing unnecessary fear and stress.

Initially we were surprised about the proportion of people requesting support for lifestyle planning; however it became a clear trend in the client group as the project developed. The project also identifies the aspiration and abilities of people with moderate dementia to make plans for their lifestyle future when clear, non-threatening communication and support is available.

### **Evaluator’s Comments**

Clients and families shared comparable perspectives of the value of planning and the Project Advocate’s role in facilitating this. More personalised plans (for now and the future) and reconnecting with family and significant others were dominant themes. Several clients and families thought the quality of planning was extending time to live at home.

“At all levels your adaptation margin shrinks and you feel overwhelmed... You cannot act if you don’t have knowledge and you need the information to have the knowledge. We discuss things... balance between adequate information and offered things... dynamic balance between how much we discuss the outside world and my total needs...”  
(Client)

"I was feeling overwhelmed... I'd probably still be wondering about guardianship and not realising how essential it is in case something goes wrong... the indirect consequence of (contact with) Project Advocate - it started a chain of events so I looked for guardian(s) with insight - the role of their life experience... now I have guardian(s) who are individual and personal to me..." (Client)

"I lost the address of a family member overseas – Project Advocate got on the internet, contacted the UK and found out where they are. She is going to help me ring overseas because it is a complicated number and I can't do it on my own."

"(Without the project advocate) I'd be in a Nursing Home or dead. I wouldn't have a quality of life...I'd be rotting away. This (living situation) isn't the bee's knees but I'm independent to a certain extent. " (Client)

"(The assistance from the project) extended the time Mum could stay at home and enjoyment of the time... Mum may well have deteriorated quicker without the help that was set up... If the Project Advocate hadn't been there it would have increased the burden for Mum and the family... we knew someone was going round and keeping an eye out... " (Family member)

The Project Advocate was frequently described as 'trustworthy'. To clients this tended to mean independent, honest and dependable support with no vested interest. For families it was related to reliability, being honest about what was happening, communicating clearly; and having no conflict of interest.

"The main thing is you don't feel alone. With Project Advocate you ring up and she's there! It's a confidence thing... you're not alone...confidence knowing things are right with your money and if you're sick she'll get in touch with your son. It's like extended family – if you had a functioning family." (Client)

"We're spread all over the world - Mum was isolated. Project Advocate provided support that some family could have done if they were around... Proactive in contacting Mum, emails to keep us in touch with what going on - not just when things were a problem - when she was doing fine too." (Family member)

"There was a 'black hole' that the Project advocate filled - the communication was vital. Project Advocate was a godsend for us." (Family member)

Improved health and reduced feelings of isolation were reported by clients; while families tended to describe their family member as having improved safety and security measures.

"The 'business part' was (already) sorted out but I talked over my circumstances and arrangements...the Project Advocate heard them more understandingly than anyone else...helped me get back in touch – reconnect with my family." (Client)

"I feel confident that (without the Project Advocate) it would have increased Mum's risk factor. When she got involved Mum was doing funny things but it settled down. Mum had great comfort in knowing that Project Advocate was there, looking out with genuine care and interest..." (Family member)

"Got my sister to have a Red Cross button - achieved a milestone.... Organised better security and house key in lock box." (Family member)

Families also commented on the project's capacity to assist them to access information and plan or follow-through on existing plans.

"Families haven't been through it before - not prepared for something like this and to deal with it. Even if family is present the Project Advocate gives a buffer for the family to deal with what they are going through. This is a vital resource for my family

and I can clearly see this is vital for a lot of families... a vital resource to the community...” (Family member)

“The plan was in action but the Project Advocate helped all the other people who saw him as confused realise that he knew what he wanted. She kept it on track.” (Family member)

### **How do we encourage people living with dementia to think about planning?**

The overall approach builds on positives as any approaches that emphasize inadequacies or failings will isolate clients and destroy trust. PLWD do not always share the sense of urgency regarding futures planning expressed by many professionals or family members. Proceed at the client’s pace - attempts to suggest or introduce a variety of support services too rapidly may cause stress.

#### **A person-centred profile – getting to know where the person is**

- Pre-planning and mapping
- Establish existing support networks
- Identify strengths, coping capacity and formal directives in place
- Note any vulnerabilities – look for specific strengths to scaffold these.

#### **Setting the planning agenda**

- Client provides clues about themes and issues that are worrying them
- Advocate identifies possible areas for client to engage in setting goals/ plans
- Advocate ‘checks’ for client interest.

#### **Deciding on plans – helping the person feel in control**

- Based on what is identified, what are the options for actions?
- The advocate assists to outline the possibilities
- The person decides the course of action
- The advocate assists with follow-through
- The person has experienced a planning cycle and feels more in control – this reinforces the value of collaborative planning.

#### **What else?**

- The advocate introduces options from the ‘menu’
- “Have you considered...” (includes formal and informal/lifestyle)
- The cycle repeats.

#### **Things to remember**

- Planning is a continuous cycle, not a ‘one-off’ event.
- The advocate needs to understand the person’s current priorities and be clearly non-judgemental with no vested interest.
- Information, involvement & support are essentials in the planning process.
- Ideas and information will need to be revisited.
- The advocate looks for opportunities to introduce planning ideas. As the relationship becomes stronger they can discuss and introduce more.
- Telling parallel stories and providing examples of what other people living with dementia have found useful can help clarify issues.

“When I get anxious I get confused... I get confused anyway I suppose... but there is an overlap. Project Advocate is well informed, well ordered. She developed a diagram of services and what they do. She has the intellectual capacity to explain things - gives an overview, picks out what is relevant and concentrates on those, gives ample anecdotal evidence and examples of what happens. She helps separate things - financial, quality of life... “

Client – Evaluation Interview

**ii. Act as an enabling guide for clients to manage transitions between service providers**

*In hospital Ruby was told by staff that she must consider permanent residential care because she lives alone, is a falls risk and therefore not safe. Ruby did not want to move to residential care. She identified her reluctance to increase the level of in home support but accepted the safety concerns expressed by the occupational therapist. Ruby requested the Project Advocate investigate her options and make a referral for a home alarm.*

*At a later discussion Ruby:*

- disclosed her struggle undressing and getting into bed at night*
- sought a new ACAT assessment to increase her level of support*
- requested the transfer from a CACP to an EACH support package.*

*The transfer resulted in the introduction of a new service provider and several new workers into her home. The Project Advocate facilitated a meeting with both providers to discuss how the process could work for Ruby. This resulted in improvements to her ongoing support, greater consultations with Ruby regarding her future care; and avoided what looked like an inevitable admission to residential care.*

**Outputs: Transitions**

Accessing Services

- 22 people assisted to introduce a variety of services into their home
- 10 clients supported to access community respite for the first time
- 9 clients assisted to access residential respite for the first time

Identifying Needs and Assessment Support

- 16 people supported in the initial decision to undertake an ACAT assessment
- 8 people assisted through reassessment to access a higher level of support
- 9 people in acute care assisted to identify security and support needs to return home
- 5 people supported to suggest solutions for needs overlooked by service providers
- 2 people supported through clean up processes to enable services to commence

## Documentary Assistance (Locate and complete application processes)

- 12 people (including some in acute care) assisted to access and complete applications for respite and permanent residential care
- 4 people assisted in applications for supported accommodation interstate to be close to family members
- 2 people to access alternative community accommodation

## Outcomes: Transitions

In the short time frame of the project, 15 people had multiple transitions and ongoing involvement around services they were receiving. Others experienced transitions but less frequently or one-off.

“(Without the Project Advocate) I'd still be in a Nursing Home...or dead. I wouldn't have a quality of life...I'd be rotting away. This (living situation) isn't the bees knees but I'm independent to a certain extent.” Client – Evaluation Interview

Many clients were not receiving services in the early stages of contact with the project. Consequently, the enabling support from the Project Advocate might involve working through the transition from previous independence to the introduction of informal or formal support in ways that enhanced lifestyle.

“Assistance that fits into my life rather than me fitting with them...”  
Client – Evaluation Interview

## Evaluator's Comments

“Dealing with dementia and aged people (particularly when they have to move) is difficult for the person and the family feels guilty. Project Advocate was someone who can communicate on both levels - with the person and the family.” (Family)

Among the clients interviewed, changes between service providers were commonly related to service boundaries or restrictions e.g. changing from a CACP to an EACH package could involve changing service providers as some organisations did not provide support staff during the evening or at weekends. For people living with dementia that are alone and then required increased support, such service provider changes occurred during times that were already stressful for them. Frequently clients and families saw the change as something that should not be necessary. However all believed that the Project Advocate's assistance during the 'unnecessary' transition between service providers made the change easier.

Several clients also referred to the number of professionals who may be involved during transition planning and the Project Advocate's ability to minimize confusion for them.

“She helps with liaison and sorts out who comes and who doesn't come so it isn't *here comes another one.*” (Client)

For frail aged or vulnerable partners, help to access respite and documentary assistance was significant:

“You have to take care of yourself, but if there's trouble with respite it's worse than not having a break. It's tempting to give in so there is no drama...” (Wife)

“I needed help and Project Advocate was there. It's hard to find the inclination to read things through... caring for my husband I couldn't find the time to fill in forms... I was tired - it was a big job looking after husband. Project Advocate helped do applications for residential care - I knew it would be private - I wasn't so sure about my family members so I couldn't ask them.” (Wife)

## Communication Strategies that Assisted within the Project

### Essential features of successful communication:

- Active listening to ensure the person feels valued
- Encouragement and feedback particularly relating to the client's strengths
- 'Space' so clients can direct discussions until they are comfortable with the advocate raising topics they might consider for the future
- Time for clients to express themselves as some PLWD may have difficulty finding words.
- Deal with one matter at a time and try not to jump between issues or change the subject
- Ask the client for their opinion
- Avoid correcting details such as times, dates etc. unless relevant as this emphasizes their memory loss/confusion
- Concentrate on identifying key words, ideas and themes of conversations
- Don't assume what the client is thinking or going to say
- Always ask and check that you have made a correct interpretation
- If the content of the client's communication is unclear, state the emotion that seems relevant to what they are saying – this understanding can assist
- Be aware of opportunities provided in conversations to explore relevant issues such as safety or stress.

### Knowing the client

The client must feel comfortable, safe and consent to meeting with the advocate.

The essential aspect of knowing a client is time spent in meaningful conversation with them and observing their skills and living arrangements. The advocate introduces themselves and the concept of advocacy as it relates to the person's situation. The relationship is described as one that empowers them through the support of the advocate to solve problems and realise their goals such as their wish to remain safely at home.

During the initial visit the advocate encourages the client to tell their story, interpret their situation and present needs if any. Questions are kept to a minimum but prompts may be provided to illicit depth of information. With client consent, notes may be taken (if required), providing they don't detract from engagement between client and advocate.

### Knowledge of the dementia process

The success of the relationship between clients and the advocate depends on the communication skills of the advocate. Central to this is using communication strategies that are known to be effective in communicating with people living with dementia; and understanding the dementia process and its individual presentation. It is also vital to appreciate the importance of each client's individual personality which overlays their presentation of dementia.

## 2. Ongoing support and issues based advocacy at all stages of the dementia spectrum

“The money situation and bills are sorted out - a big worry gone! My health is much better. Communication with my son is better because Project Advocate can be involved - can pressure my son for a more timely response - he has Power of Attorney...Project Advocate will fight for you, keep you home and keep your family together.” Client – Evaluation Interview

### i. Advocate for clients on issues and problems of concern to them

*Kevin is in his eighties and is aware of his memory loss. His stepdaughter Sarah lives interstate where Kevin previously lived. She is Kevin's only relative. Several years ago they discussed him selling his home to move close to Sarah when he thought 'the time was right'. Both felt this was the plan. A social worker assisting Kevin with temporary accommodation questioned his capacity to sign the contract of sale and thought Kevin was being pressured to sell the house. Kevin requested assistance from the Project Advocate who supported him through the process of a psycho geriatric assessment of his capacity to understand the nature of the contract; and its implication for his financial future and accommodation options. Kevin also requested the advocate liaise with Sarah and advocate with lawyers and other parties to achieve his goal to relocate interstate.*

### Outputs: Advocacy

#### Protecting Rights and Preventing Further Abuse

- 6 people empowered to stop their emotional and financial exploitation by others
- 3 people supported to consider options for dealing with emotional abuse
- 5 clients supported through disputes with family members to protect their right to participation in decision-making processes.

#### Health and Well-Being

- 26 people assisted to access and attend medical, dental, hospital and other essential appointments on at least one occasion

#### Protecting Legal / Financial Rights

- 16 people supported to continue independently managing basic financial matters such as paying accounts, banking or shopping to safeguard their rights and protect them from financial exploitation.
- 8 people assisted to communicate with lawyers, understand areas where decisions need to be made with legal matters
- 2 supported during court appearances on at least one occasion.

#### Service User Rights

- 7 people empowered to discuss and resolve issues with their service providers
- Liaison with service providers in relation to the wishes and delivery of care for 38 clients

## Outcomes: Advocacy

*At 85 years of age, Dorothy rarely leaves her home. She requested contact with the Project Advocate following discussions with her CACP provider who was concerned regarding Dorothy's finances. Her neighbour usually goes to the bank to withdraw money and complete Dorothy's shopping, but Dorothy suspects she is being financially abused and there is no accountability for money received or spent... Dorothy asks the Project Advocate to approach the service provider and the bank. A worker is authorized to make withdrawals, complete shopping and keep a record of money spent at Dorothy's request.*

Consultations with a range of legal and health professionals are significant events for clients. While assistance with professional appointments is not normally provided by advocacy services, it was a vital function of the Project Advocate because people are asked to make significant decisions on the basis of these appointments. Assistance became a means to help the client maintain control over their life.

*Jack says he would have missed out on a lot of help if the Project Advocate hadn't been involved. He was surprised and pleased with the assistance to talk with his doctor and believes this prevented a lot of arguments.*

### Evaluator's Comments

The independent evaluation data captures a high level of client and family satisfaction with the process and outcomes of advocacy support. Many of the contexts were high order, complex, extremely problematic situations. All clients interviewed reported the Project Advocate sorted out a major issue and/or an abuse issue was addressed.

"Things change with your relationships with memory loss... family abuse you - can't do anything for you." (Client)

"To know for peace of mind there's Advocacy... somebody to defend and look after your rights..." (Client)

"Without the Project Advocate I probably would have bolted - or been in the funny farm - or violence... I don't know where I would have been - probably some stinky little home... I would have been lost without her." (Client)

Families reported relief that issues were usually resolved or strategies put in place to better manage them. Significantly, clients and family members commented on learning from the Project Advocate's approach to problems of concern.

"I've learned to take care of what is important at that time; not to sweat the small stuff; and that no one is so important that they can take over your life." (Client)

"Someone like the Project Advocate informs you of your rights e.g. emergency guardianship order, chasing the Public Trustee. I was let down by the police (with limited follow-up with other abusive family members) but now I know there is more I can do..." (Family member)

One family identified tension regarding future directions:

"My sister wants to stay at home and this is being achieved at present. My peace of mind (that her goal is being achieved) is overtaken by my concern for practical house arrangements that are needed now and will be necessary in the future. I'm over 80, the house hasn't been sorted out for 3 generations, it needs maintenance – I suppose it will be the grandchildren's problem.." (Family member)

## **How does the Project Advocate support people within appointments with professionals and in subsequent decision making?**

### **Preparation for appointments**

- Prior discussion and explanation of the purpose and aims of the meeting
- Clarifying issues to be raised ensure the client is empowered and the advocate understands
- Discussion regarding the client's expectations and preferred level of communication during the consultation
- Consideration of possible outcomes of the appointment (if appropriate)

Clients are encouraged to speak on their own behalf and are empowered with strategies to do this if they wish. These can include rehearsal of what they want to say and using prompts. Preparation for appointments may often include the advocate having preliminary conversation with professionals regarding the purpose of the consultation.

### **Putting the client at the centre**

The advocate ensures the client is always placed at the centre of attention by:

- Ensuring the client enters the consulting room first
- Permitting the professional to greet the client before introducing themselves
- Checking that seating arrangements are appropriate
- Allowing the client to respond without interruption
- Encouraging the consultation to proceed, as it would normally happen.

Professionals usually address the client directly, particularly if they have a long-standing relationship with their client. If not, the advocate directs attention to the client and models appropriate ways of interacting and communicating with them.

Where a client does not raise previously discussed issues or concerns the advocate prompts them or asks if they are happy for the advocate to provide details. A point is made that the client is free to interrupt the advocate if they wish.

When the advocate speaks on the client's behalf they check they still have the client's consent despite any prior agreement. This respects the client's right to change their mind and gives them maximum choice in what does or does not happen. It also guarantees the professional is aware of the client's consent.

### **Following the consultation**

Follow-up discussion with the client should take place as soon after the consultation as possible to capitalize on the immediacy of new information. Clients will require time to discuss options and possible consequences of their decisions.

The advocate should discourage the client from making hurried decisions about major decisions or life changes. The information, content and need for decision-making should be revisited as many times as necessary. The aim should always be for the client to be comfortable making important decisions about their future.

### 3. Systemic development of pathways and smooth transition with service providers

#### i. Identify barriers to client's voice being heard in transitions and assessment processes and document examples of good practice.

##### **Outputs: Barriers to client voice**

Throughout the project there were numerous opportunities to notice barriers to client's voices being heard. In addition to the experiences, ideas, suggestions and reaction from clients in the project, data also came from the project Reference Group, the Regional Dementia Network and from information provided by stakeholders during the project and through the evaluation process. It is clear that people living with dementia want their voice heard during all aspects of their lives.

##### **Outcomes: Barriers to client voice**

Values and attitudes to dementia and ageing influence how people are treated

- PLWD being seen as not possessing the cognitive capacity to make decisions
- Assumption that difficulty making decisions in some life areas means the person will have difficulty in all
- PLWD making plans for their life is often seen as unnecessary or its importance is underestimated.

Vulnerability and diminished control

- For many clients the label of dementia meant they could not be trusted - other people's priorities were more important
- Priorities about safety and control add to PLWD's anguish
- Families are often not supportive and positive; and are sometimes abusive. In some situations outside involvement is perceived as threatening the control they have over the person
- PLWD are often disconnected from relationships and isolated within the community increasing their risk of abuse (Isolation is a commonly recognized strategy in Elder Abuse literature)
- The perceived need to "protect" PLWD removes opportunities for normal behaviour, which for this group may be labelled as "risk taking."

Quality communication: skills and time

- Communicating with PLWD is complex and presents challenges on both sides
- Generally there is inadequate understanding of strategies for effective and meaningful communication
- Insufficient recognition of the time PLWD may need have their voice listened to, interpreted and understood
- Lack of time inhibits PLWD from self-disclosure of needs and other insights into their lives resulting in valuable information being overlooked.

Impact of medical models

- Dementia has been seen as a medical/mental health issue meaning psycho-social issues are may be inadequately considered and be unheard

Attitudes and behaviour of elderly people

- The generation of people currently with dementia may perceive doctors and lawyers as authority figures which causes them to defer to them
- A number of PLWD expressed that prior to their involvement in the project they lacked opportunities to self-advocate about issues of importance to them. Consequently they had limited experience and practice in being heard.

### Situational pressure

- Some services are reluctant to communicate with PLWD and in the absence of family and other contacts take on an unauthorised surrogate decision making role
- Negative family relationships with unresolved disputes and competing agendas hence the voice of the PLWD is ignored or discouraged.

### Evaluator's Comments

Feedback from clients and families about what the Project Advocate does to help people living with dementia become involved offers some interesting insights into what good practice may look like:

#### Clients:

"Explains things well. Has time so doesn't rush me or make me anxious..."

"Doesn't muck around. Talks clearly."

"Non-threatening. Initiates contact and doesn't assume."

"Liaises with others and helps with communication/streamlining things."

"Sorts things out and makes it clear for me."

"Clarifies things. Respects different perspectives. Uses visuals."

"Project Advocate wants to be helpful. She's practical."

"Gives an overview, picks out what is relevant and concentrates on those, gives ample anecdotal evidence and examples of what happens."

"Helps separate things - financial, quality of life..."

#### Families:

"Had a knack and way of communicating with family member that wasn't stressful."

"Sensitive, non-judgmental, listened - didn't make own 'diagnosis' or opinion - listened - understood what he really wanted."

"Helped her understand the options and decisions that she needed to be aware of."

"Like a member of the family or very good friend (who helps get things done)"

"Floats ideas and then follows up on them...has a way of getting things done."

"Sister unable to think forward and can get 'aggro' about ideas – Project Advocate managed to present things in ways that she considered them."

## 4. Education of stakeholders regarding rights of people with dementia

### *i. Provide education to stakeholders regarding the rights of people with dementia*

#### **Outputs: Education regarding rights of people with dementia**

Information Sessions initiated by the Project:

- AAT staff
- ACAT assessors and Community Options case managers
- Community Health Nurses x 6 regions
- Community social workers and allied health providers x3 regions
- Southern region HACC service provider forum
- “ “ CACP & EACH provider forum
- Acute Care aged care nurse specialist at 5 sites
- Acute Care and outreach allied health and social workers x 2 sites

Education sessions requested:

- Nursing and medical students
- Carers of PLWD x 2 sessions
- Southern Region of General Practice
- Southern Region Health Promotion Forum
- Kingston Seniors Action Group

+

- Newspaper articles x2
- TV interviews for news item x2

#### **Outcomes: Education regarding rights of people with dementia**

The project successfully informed 350+ people about the project, its rationale and aims resulting in increased awareness of the rights of people living with dementia. The sessions with major stakeholders, combined with an article in the General Practitioner newsletter resulted in referrals and participant numbers exceeding expectations.

Follow-up education sessions will share the findings of the project and inform future practice. We were naïve in thinking we could do this during the live part of the project.

The project has resulted in ongoing relationships e.g. General Practice South Dementia – an educational series addressing – assessment, communication, outcomes, referral, needs and empathy. A five part, two hour series of sessions to General Practitioners, ACF nurses, pharmacists and relevant health professionals. Facilitated by the General Practice (South).

*ii. Document improvements in the aged care sector which promote the rights of people with dementia.*

**Outputs: Improvements which promote the rights of people with dementia**

- Feedback from service provider survey re changes attributable to the project
- Analysis of documented discussion from Reference Group

**Outcomes: Documented improvements promoting rights of people with dementia**

Improvements in the local aged care sector as a consequence of the project include and are evidenced by:

- An increase in appropriate referrals for the target group as the project progressed indicates growing awareness and understanding of the importance of advocacy and its role in protecting the rights of vulnerable individuals.
- The project broadened service provider's perspective of the advocacy role.
- As a consequence of the involvement of the Division of General Practice on the project Reference Group, aspects of the challenges of supporting PLWD who live alone in the community have been incorporated into a five session series of workshops for GPs and health professionals.
- Five major service providers and representatives from the acute care sector collaborated to fund an information session to carers covering "What to Expect when PLWD go to Hospital". This stemmed directly from Project Advocate sessions and dialogue.
- The five service providers have committed to deliver more sessions – first follow-up has already happened.

It is anticipated that when the learnings from the project are widely delivered to service providers via proposed information sessions, further significant sector improvements will follow for PLWD.

**Evaluator's Comments**

The independent survey of service providers indicates increasing knowledge and awareness of the rights of people living with dementia and the role the advocate can play. While positive change in service practice is harder to ascertain at this stage (and is probably premature), the main improvement service providers identified regarding their own practice was around referral and recognizing when people living with dementia would benefit from the service.

"It has provided a person to whom to refer to (re) difficult financial and legal matters in relation to clients with dementia"

"Able to refer people on to a service that will be beneficial. At the same time allows our time to be spent in other areas"

"Client's are referred quicker to the (advocacy) service when issues are identified"

"Following education sessions staff are more aware of the Dementia Advocate and how and when to access the service. Staff are more aware of the clients rights."

"Greater interaction with the Advocates to give advice"

"More confidence that the rights of people with dementia will be protected in the community"

"Would like the dementia specific advocate back as with her background knowledge of dementia I have more trust in referring to her than another advocate."

"Nothing at an organisational level but some changes (with how we about support) for individual clients"

"Sharing of information between service providers."

## Significant findings, if any, arising out of the Project

- 1) Access to help, advice and supports as early as possible improves the quality of life for the person living with dementia, appears to slow the disabling impact of dementia (through reduced stress, solved problems and better health care management); and delays the need to enter residential care.
- 2) People living with dementia are able to participate in planning and decision-making about many aspects of their life when they have access to appropriate information and support. They value their right to retain some control over their lives and want to preserve a sense of self-determination.
- 3) The theoretical base and experiential underpinnings of the project, combined with the action research/learning methodology resulted in and identified process that is effective when working with people living with dementia and can be reproduced.  
The critical features/characteristics are:
  - Person centred approach
  - Maximising independence and building on strengths
  - Focus on decision making and control
  - Planning as a strategy
  - Effective communication
  - The independence of the advocate.
- 4) For a number of clients experiencing abuse (particularly financial) the planning and advocacy elements were effective methods in responding to and preventing further abuse.
- 5) People living with dementia who are alone may have 'lost' connection with family and community but reconnection can be facilitated surprisingly easily with positive impact on quality of life.
- 6) Many barriers to the voice of people living with dementia are societal factors rather than related to the person's condition of dementia.
- 7) Having support from the Project Advocate increased the credibility of people living with dementia and their opinions by strengthening their voice and giving an additional voice. The presence of an advocate has an educative effect in sending a message about recognizing the person has a right.

## **Suggestions as to how the Project's findings could be applied in the health and aged care sector elsewhere in Australia**

1. An overall early intervention program that targets people living with dementia as soon as possible after diagnosis that includes provision of access to independent dementia-specific advocacy services.
2. The style of interaction between services and people living with dementia to include a stronger consumer rights focus and meaningful consumer participation.
3. Models of working with people living with dementia to take a person-centred holistic approach that is consistent with emerging discourse in community care around well-being, wellness and capacity building.
4. Holistic approaches to include taking the lead from the person, assessing and responding to issues of social isolation; and focussed efforts to connect people living with dementia who live alone in the community with someone.
5. The importance of the advocacy role that many existing case management services have should be realised and refined. Education about the principles of advocacy, the nature of dementia and the special needs of PLWD is essential for effective advocacy should be included in this strategy.
6. Services developing relationships with advocacy services and actively encouraging clients to use advocacy services.

## **The implications of the Project's findings for the Australian Government's aged care policies and programs**

1. More policy focus on people living with dementia who are alone and without supports:
  - Identification
  - Introducing supports as early as possible
2. Require services to evidence consumer input into decision-making and planning as a quality element of accreditation
3. Maintain and sustain the policy position around wellness and capacity:
  - Provide additional resources to help build capacity of organisations to build capacity of people
4. The Federal government assume a more active role in policy development for prevention and response to community-based Elder Abuse
5. Policy development that is consistent with the wellness model in promoting acceptance of the community sector's role in overcoming social isolation
6. Public Awareness campaign that presents a positive image of people living with dementia and affirms their rights to continue to make decisions about their life
7. Recognise via policy and programs the potential importance of advocates' contributions in supporting this client group in the community
8. Strategy to encourage all adults to make advanced directives for future lifestyle and financial options such as Wills, Enduring Power of Attorneys, Guardianship and Advanced Medical Directives
9. Development of standardized approaches to assessment of decision-making capacity.

## Conclusion

The Rights of People with Dementia and Advocacy Project was highly successful in filling an unmet need for people living with dementia who are alone. In addition to meeting its aims and objectives, the pilot project confirmed the anticipated outcomes and likely benefits:

1. Improved health and well-being of clients; and reduction of self-neglect through timely support, guidance and referral
2. Greater client input into care planning –for Residential Care and Aged Care providers
3. Reduced financial and emotional abuse of clients through proactive planning
4. Client satisfaction with services
5. Better support to carers and families enabling clients to live at home for longer
6. Reduced carer stress and overall pressure on families possibly reducing the likelihood of carer abuse
7. Improved service provider responsiveness to the needs of people with dementia
8. Increased community awareness of dementia and the rights of people with dementia.

The lived experience of the project demonstrated more outputs and a wider range of outcomes than originally anticipated.

The potential of the project for broader application is recognized in Home and Community Care providing funding to enable the project to continue until the end of 2008 and examining potential to extend it across Tasmania.

## Glossary

<b>ATI</b>	Advocacy Tasmania Incorporated
<b>AAT</b>	Alzheimer's Australia Tasmania
<b>ACAT</b>	Aged Care Assessment Team
<b>AMD</b>	Advanced Medical Directives
<b>CACP</b>	Community Aged Care Package
<b>CALD</b>	Culturally and Linguistically Diverse
<b>Clients</b>	People who have accessed advocacy services via a referral to the project
<b>COPS</b>	Community Options Service
<b>EACH</b>	Extended Aged Care at Home
<b>EACHD</b>	Extended Aged Care at Home Dementia Care Package
<b>EG</b>	Enduring Guardianship
<b>EPOA</b>	Enduring Power of Attorney
<b>GAB</b>	Guardianship and Administration Board
<b>LWML</b>	AAT – Living With Memory Loss Program
<b>PLWD</b>	People Living with Dementia
<b>RHH</b>	Royal Hobart Hospital