

Talk to COTA WA Conference – 8th June, 2010

‘Alzheimer’s, dementia and consumer directedness’ presented by Anne Deck, Manager Support Services, Alzheimer’s Australia WA Ltd.

Definition of Consumer Directed Care

Consumer directed care empowers people with disabilities to make decisions about the services they want and how they wish to receive them.

Maximises consumers’ ability to assess their own needs, determine how and by whom they are met and define what constitutes quality – AARP Public Policy Institute – Washington DC

It is a philosophy and an orientation to a service delivery option where consumers control and choose the services they get, including what, when, how and where and who provides those services – Aged Care Services Aust

Two words that could sum up Consumer Directed Care is choice and control or empowering people.

It would be assumed that to do this would require the person to have a level of cognition or capacity to make an informed choice.

Definition of Dementia

Dementia is a progressive decline in brain function that over a period of time affects a persons ability to make decisions due to short term memory loss, confusion, loss of awareness, loss of communication skills, loss of decision making ability – also seen as having reduced cognitive capacity.

So how can Consumer Directed Care fit with a person who has dementia?

Perhaps the question is

How can Consumer Directed Care programs be made ‘dementia friendly’?

I am not going to pretend that I have worked out the answer

I am going to take a lot of my information from a position paper produced by Alzheimers Australia written by Dr Jane Tilly and Glenn Rees, CEO of AA in 2007

There is evidence to suggest that Consumer Directed Care offers participants better outcomes related to quality of life, independence and satisfaction with care and control.

Dementia is associated with decline in quality of life and loss of independence which can lead to depression – so if it is possible to adapt Consumer Directed

Care principles to support people with dementia then it may be that there is a better quality of life and support for maintaining some independence.

What are the possible challenge we could anticipate?

For the person with dementia

Changes in personality, may become withdrawn, experience agitation, for some wander away from home unsupervised. As the dementia becomes more advanced then the needs of the person with dementia increase – assistance with personal care, eating and other daily activities.

For the family carer there is physical, emotional and financial stress.

So how do we make Consumer Directed Care program dementia friendly?

It's a bit like a jigsaw puzzle – how do we make the pieces all fit together to be complete – so that we can see the big picture.

The first piece of the jigsaw is

a) **Choice** – As mentioned previously choice is about having control. People with dementia and their family members should have available to them options. Do they want some control over their services or would prefer not to take on extra responsibilities?

b) **Assessment** – before any program is offered there is an assessment. As with Consumer Directed Care the process is to determine the level of cognitive impairment and whether the person needs help in managing services or needs to choose a representative to manage services. As the dementia declines then reassessment of capacity to manage services would be critical. Assessment would also consider the needs of the family carer and connect the family carer with support services identified. So the assessment process would require good up to date information on what is available to assist the person with dementia and the family carer make choices that give them an improved quality of life. Relevant, user friendly information would be critical. It would be appropriate to involve consumers in this process.

c) **Representative Responsibilities**

In most Consumer Directed Care programs a participant regardless of whether a person has dementia or not would ask a representative to help them manage their care. The amount the representative would be involved would be dependent on the cognitive ability of the person wanting services. As no two dementia's are the same this again is a very individual decision – but it is about choice and valuing a persons desire to have some involvement in decision making. This in turn assists a person to have some control over their life where possible.

CHOICE CONTROL INDEPENDENCE

Who would be a representative? As with any person who has Consumer Directed Care package it would be

- Someone who knows the person – family or friend
- Has a consistent presence in the persons life

What might be their responsibilities? Again – as with any person who has Consumer Directed Care package it would require

- Recruiting, hiring and training
- Manage individual workers who could be family or friends
- Ensuring the preferences of the person with dementia are known

d) Training –

The focus of the training would centre around person centred care in relation to dementia

Who?

- For all people involved in delivering the Consumer Directed Care program
 - Family, friends
 - care coordinators
 - assessors
 - paid carer

What?

- A knowledge of dementia care – strategies for dealing with unsafe wandering or managing challenging behaviours
- Principles of consumer direction
- How to handle management tasks – recruitment (could be family or friends), supervision, responsibilities for oversight, payment etc
- For assessors and service coordinators - recognising signs of abuse or neglect of consumers – mandatory duty to report

e) Quality assurance

Service provider would be key in this piece of the jigsaw

It would require a shared responsibility with service coordinators and participants

Consumers or their representative would need to hire qualified workers and train them to deliver appropriate care for a person with dementia – would require an understanding of dementia.

Service coordinators are in periodic contact with consumers and their representative to provide assistance when needed and help with resolving any issues that may arise.

Contact with participant and their representative would need to be regular to ensure that any problems are detected. This contact would need to continue even when things are going OK because as the dementia progresses there will be changes which may change the service

f) Financial Management

Spending needs to be designed to meet the care needs of the recipient
How can this be done?

Budget to plan and cover what is required

Some CDC programs provide financial management service to help participant to train and pay workers, tax withholding and related functions, bills for other services such as home modifications.

It would be fair to say that most people do not want the added stress of managing finances unless this is one of their skills. The challenge is not to add stress but involve the person or their representative at the level they want to be involved. It would be a bit like having an accountant.

So these are some of the key pieces in the jigsaw

How do we start implementing Consumer Directed Care programs and then further develop the concept for people living with dementia? For some consumers it could improve their quality of life.

It's a bit like NAVEL GAZING – we need to move from contemplating to making a start.

We already have some structures in place which allows carers to purchase whatever goods or services are needed – with no restrictions – Carers Allowance

We already have teams in place who assess needs of people requiring care and support in the community and ongoing – ACAT

We already have a philosophy amongst aged care providers who pride themselves in offering 'client-centred care' – it could be argued how much of a say consumers have in the type of services/care they receive, how it is provided – is this empowering?

We already have community care programs funded by Commonwealth and State – HACC, CAPS, EACH and EACHD which has a cashed out benefit for a case manager to provide or purchase services for the care recipient - only a small step for the care recipient or carer to manage his or her own care with a cashed out subsidy.

We already have brokerage funds available through the National Respite for Carers program and Career Respite Centres – just a small step for the care

recipient or carer to determine how the money could be spent for themselves.

We can even extend CDC to decision about whether a person wants to receive services in a resi facility or at home.

So you can see many of the structures are already in place it is just a matter of how to shift the focus – look at things differently – think outside the square.

Yes it would be a challenge. We as service providers would probably need to be more accountable, better engaged with the person with dementia requiring services/support.

It would also require that information about services be available for people living with dementia to make choices. In order for the best choices to be made people require clear relevant information and then if they need assistance in making choices then an organisation that is able to best support the person living with dementia with that information.

So if we are Navel gazing what would it take to continue to move down the Consumer Directed Care pathway?

We have the **Consumers** and we have the **Care packages** what we need to change is the **Directedness**.

A challenge for Government and service providers to get their head around but a worthwhile challenge