

House of Representatives Standing Committee on Health & Ageing

Inquiry into Dementia: Early Diagnosis & Intervention & how they can-

- improve quality of life and assist people with dementia to remain independent for as long as possible;
- increase opportunities for continued social engagement and community participation for people with dementia;
- help people with dementia and their carers to plan for their futures, including organising financial and legal affairs and preparing for longer-term or more intensive care requirements; and
- how best to deliver awareness and communication on dementia and dementia-related services into the community.

A submission from Community Care Services-Central Coast Ltd

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Community Care Services-Central Coast Ltd (CCS) welcomes this Parliamentary Inquiry into early diagnosis and intervention of dementia. Our submission presents comments and recommendations to the enquiry particularly relating to -

- improving the quality of life and assisting people with dementia to remain independent for as long as possible;
- increasing opportunities for continued social engagement and community participation for people with dementia.

CCS is a local community provider of Home & Community Care (HACC), National Respite for Carer (NRCP) and Veterans Home Care (VHC) programs and has been servicing the needs of the frail aged, people with dementia and their carers for the past twenty seven years. Our experience in assisting a person living with dementia and /or their carer includes –

- Operation of three (3) dementia specific day centres –Gosford, Woy Woy & Gorokan
- Dementia specific “in-home” carer respite
- Dementia specific Social Support –our “Lone Livers” program is tailored specifically for a person with dementia living alone & who, at times , may not have the assistance or support of a close relative or family friend.
- Memory Lane-*Doing Things Together* a recently introduced activity and forming the basis of this submission.

Since its founding, CCS has sought to respond to the needs of the ageing communities in the Gosford & Wyong LGA’s particularly reaching out to assist people living with dementia and their carers, as the emerging needs of this group led to the founding of the organisation in 1986.

The benefits of developing and maintaining friendships & social connectedness (improved overall health & well-being etc.) are well documented, as have the consequences of social isolation (anxiety, depression, anger and poorer physical health). Unfortunately, equally well documented is how the impact of a diagnosis of dementia takes its toll on social relationships, with, friends and/or family members withdrawing and ‘disappearing’ because they can no longer bear to see the changes that are taking place in their diagnosed friend or relative and further adding to the person’s feelings of depression, abandonment and otherness.

On the other hand friendships and other types of social supports have been found to have a positive impact on the dementia experience. Maintaining &/or establishing new friendships can assist a person with dementia and/or their carers to maintain a sense of identity and purpose. Having close social connections with friends and families can act as a protective factor against some of the devastating effects of dementia, physiologically, socially as well as functionally.

Unfortunately it is not always possible for a person with dementia to access mainstream activities in the community due to fear of embarrassment by the carer of their loved one exhibiting challenging behaviours. As a consequence caregivers tend to sacrifice their leisure pursuits and hobbies and may even restrict time with family & friends in order to support the ever increasing demands of their loved one.

As indicated above our organisation provides “traditional” respite to carers via dementia specific day centres as well as in home respite however there is emerging evidence to suggest that “respite” away from their loved one, is not always in the best interests of the person with dementia or their carer. This is validated by our own carer surveys where carers, whilst appreciative of “traditional” respite being provided, expressed a desire to be able to continue to socialise with their loved ones in familiar community settings but where such settings also offered safety, security and support in their caring role. This unmet need is further evidenced with advice from Clinical Nurse Consultants, from the Central Coast Dementia Advisory Service reporting they are continually being asked at Carers Group meetings “what can we do together” and requiring the response “there is currently no service on the Central Coast that can support carers in this way”.

Responding to this unmet need, our organisation sort to implement a series of activities that provide couples living with dementia an opportunity to participate jointly in a range of social activities. The basis of activities being developed are founded in research material relating to the Alzheimer’s Café model of community support , first introduced in 1997 in the Netherlands. A distinct feature of the Café service is that both the person with dementia and their carer, family member or friend participates in the activity. Research suggests that there are substantial individual & social benefits to be gained from this style of activity and other similar social interventions for people with dementia & their families and carers (Cook 2001; Brodaty 2003; Smits 2007)

Our pilot program Memory Lane-*Doing things together*, whilst not readily recognised within existing traditional HACC/NRCP models of carer and/or care recipient support, seeks to address a request for alternate forms of “respite”. Our initial activity, Memory Lane Restaurant, commenced at our Woy Woy centre in February 2011. A second restaurant commenced at our Gorokan centre in August 2012.

Carers acknowledge maintaining ‘cover up skills’ in a mainstream setting, can be very stressful and tiring for their loved one, and they may not want to attend social outings, even family functions. But there are no such restrictions at the Memory Lane Restaurant setting, where everyone is accepted and appreciated for who they are. The pressure is diffused for both the person with dementia and their carer.

Restaurant customers (up to 8 couples living with dementia per sitting) have generally emphasised the social benefits of this activity - an appreciation of the dining experience, meeting people and making new friends. Specific feedback has included -

“a wife/carer after attending a Memory Lane Restaurant, spoke of the joy she felt laying out their ‘good’ clothes to go out together as a couple. It evoked memories of a happier, more carefree time in their lives, when they were ‘courting’.”

“several carers have sent us the powerful message ‘whatever time we have left we want to spend it together’.”

“life should not end with a diagnosis of dementia. Social interaction, social opportunities and quality of life should remain available, and if necessary, in a supportive and safe environment such as the Memory Lane – Doing Things Together Program.”

"firm friendships have been formed at the Memory Lane Restaurant luncheons and dinners, by attendees in a similar position. Telephone numbers are exchanged with a promise of 'getting in touch'."

Additional "Doing Things Together" activities are now being planned with a number Memory Lane Cafés to be shortly established and a Memory Lane Leisure group to be formed in early 2013.

The benefits of early diagnosis and intervention for a person with dementia and their carer are undeniable but what support and assistance is then to be provided remains a vexed question.

Our organisation has developed strong working relationships with other dementia services on the Central Coast in particular the Central Coast Local Health District - Dementia Advisory Service, who manage multiple Carer Support Groups across the Central Coast. Following a diagnosis of dementia, GP's and Geriatricians refer carers to these support groups and/or the DAS team and, in turn, they are referred to HACC / NRCP funded providers for traditional community and/or residential respite care.

Local carer feedback, research associated with the Alzheimer's Café model and success to date of the Memory Lane – "Doing Things Together" project clearly indicate that carers of a person with dementia seek flexible respite options and arrangements in place where "respite" may not necessarily mean "taking a break" from their loved one.

Recommendation

Future funding models in Dementia Community Care be expanded to allow flexible respite options that support and encourage personalised choice of carers.