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ANGLICAN AGED CARE SERVICES GROUP (TRADING AS “BENETAS”)

RESPONSE TO INQUIRY INTO DEMENTIA EARLY DIAGNOSIS AND INTERVENTION

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1. Introduction

This whole area is of great interest to Benetas and we are well aware that the vast majority of our residential aged care residents, as well as a number of our community care clients, suffer from some form of dementia. As a result we have initiated a number of programs aimed specifically at assisting these people and their families. A constant issue that we continue to face is the general lack of knowledge of dementia and the difficulties people face in trying to obtain an early diagnosis and subsequent necessary supports. Consequently we welcome the Inquiry into Dementia Early Diagnosis and Intervention and the following is our response to the Inquiry based on its terms of reference.

2.. How to best deliver awareness and communication on dementia and dementia related services into the community

We believe there are two issues arising out of this term of reference. One is the education of the general community about dementia and attempting to dispel the stigma associated with the disease. The second is about ensuring information about dementia and relevant services are readily available to the public so that families of people with signs of early dementia, and the people themselves, can easily access this information.

2.1 Education of the general community

It is our experience that any education program about dementia has to be carefully targeted and if community attitudes towards, and understanding of, dementia are to change then a key group to focus on is that of young people**.** We believe that an effective method of educating the general community about dementia is for older people to interact with the younger generations and exchange their different life experiences, including the onset of dementia.

In this regard a suggested strategy is for volunteers who have a good grasp of dementia, or even people in the early stages of dementia with a knowledge of the disease, could visit schools and talk with young people about dementia. An education pack could be developed which could be based on existing resources which are currently used by Alzheimer's Association, such as a dementia knowledge questionnaire and an explanatory DVD.

Another method which we at Benetas are just commencing is for groups of school children to visit our residential aged care facilities and engage in activities with people with dementia. At the same time staff are able to inform the students about the disease. One interesting project which we hope to commence soon is to have school students join in a choir with people with dementia at our residential aged care facilities. The purpose of these choirs is to not only encourage intergenerational social connections but also for younger people to have an experience of mixing socially with people with dementia and learn more about the disease.

2.2 Information about dementia and relevant services

Benetas recently conducted a project aimed at making mealtimes more enjoyable for people with dementia and their families. These people with dementia were living at home and were from Cultural and Linguistically Diverse (CALD) backgrounds. Among our findings were that clients and carers had a surprising lack of knowledge and information about dementia even where the clients were in an advanced stage of dementia. People reported that they were not aware of relevant internet sites, and even when they were, they said they found them quite difficult to understand and navigate. They also said they often received some information from General Practitioners (GPs) but did not receive any ongoing support, and found it extremely difficult to obtain proper assessments and diagnosis.

These finding support the result of many other studies such as the recently released report from Alzheimer's Australia "Effective Consumer Engagement in the Aged Care Reform Process".

Another issue raised in our study was the question of language, not just difficulties in understanding English terms and the need for translation of materials, but also use of the term "Dementia". Many people found that it was too final in its implications and thought that once a person was labelled with dementia there was really nothing that could be done for them. They also thought it dehumanised the person and doesn't reflect the uniqueness of each care.

As a result of these findings, and those of other reports, we believe there is a need for a single point of information and assessment and hopefully the new Gateway as recently announced as part of the Aged Care Reforms will meet this need. However care will need to be taken as to how, and in what form, this information is provided. Terms such as "memory loss and confusion" could be added to "dementia" to soften and personalise the diagnosis. The information needs to be concise and easy to understand, as well as being available in different languages. Also information needs to be provided on local services so that the callers can easily access these services.

It is clear that as dementia is a journey through stages people need ongoing access to services and need to form ongoing relationships with local service providers. In particular we found the role of a case manager is of particular benefit to people to assist them to navigate the system and be able to access services and obtain information as required.

3. Improve quality of life and assist people with dementia to remain independent for as long as possible.

Numerous studies have found that people wanted to keep living at home for as long as possible and clearly appropriate level of services and support need to be available for this to occur. However, in this regard, we have found that there is a widely held perception, even among some health and aged service providers, that once a person is diagnosed with dementia that it is a downward spiral and there is really nothing one can do except try and deal with the symptoms. This understanding of dementia is often reinforced when carers lack support and reach a stage where they feel overwhelmed and unable to cope. As a result there can be premature admissions into residential aged care which can be distressing for the person with dementia and their families.

In general we believe there needs to be a much greater focus on a person's wellness and on maintaining their health, skills and interests rather than just trying to deal with their deficiencies. For example, homes can be made much more friendly for people with dementia by carers and families obtaining advice on home modifications such as reducing clutter, altering the lighting, using only simple appliances and using notices. Also greater use could be made of technology such as sensors and tracing devices to give people with dementia a greater feeling of independence. Carers and families could be encouraged to develop the person's good habits and institute routines to assist with memory loss, such as regular exercise programs, participate in living with memory loss programs, continuing to attend social groups and learning to use taxis. Systems could be developed to manage mail, telephone messages and other written communication such as keeping all items and information in the one location in a house.

These strategies are easy to develop and families just need some interventions and information from specialised service providers, such as an Occupational Therapist, to implement them. These specialised service providers would be able to provide tools and resources to carers to assist with this restorative care approach which, in many cases, would be of more value in terms of quality of life and independence of the person with dementia than clinical and medical advice.

In order to further support this focus on wellness and restorative care assessment tools could be developed which not only look at clinical, cognitive and functional issues but also assess the client and family understanding of the diagnosis of dementia. Such an assessment would address key criteria such as knowledge of dementia, stigma associated with the disease, empowerment of the person with dementia and social inclusion for client and family.

While we have put forward that there needs to be a strong focus on wellness and strengths of the person with dementia there also needs to be a strong focus on support and care for the carer. The burden of caring for someone with dementia has been well documented, and it has been our experience that the further the disease progresses the higher becomes the demands on the carer. We have found that a key component of this carer burden is social isolation as the carer gradually becomes more excluded from supports, local community and following personal interests.

Consequently Benetas, in conjunction with Alzheimer's Australia Victoria, has developed a number of carer support groups in Gippsland in order to alleviate the social isolation experienced by carers of people with dementia. These carer support groups have not only enabled carers to connect with their local community and provide much needed social interaction, they also act as mutual support groups where carers learn from one another and gain support from each other. In addition health and aged care professionals visit the groups and provide up to date information on dementia and related care strategies. It is intended to develop more of these groups in other parts of the State.

These support groups are particularly effective and efficient. Carers have commented on how they have assisted them in their caring role and general welfare and overall raised their spirits so they can continue to care for the person with dementia and maintain the independence of this person. Also the groups require minimal financial support as they are virtually self-sustaining and need only a venue and some input from various professional workers.

We believe that adopting an approach which emphasises the wellness of a person with dementia and developing low cost and effective carer support strategies, such as carer support groups, will go a long way to improving the quality of life and maximising the independence of people with dementia.

A particular group of people who need special assistance are those who are diagnosed with dementia but who live on their own with no carer, family or known supports. Given this situation the first step is often to move these people into residential aged care, although with some supports they could live independently in the community. Services could make better use of volunteers and local community resources to provide these supports and often it is just a case of undertaking a more detailed, and person centred care, assessment to discover that the person living on their own does have friends and neighbours who can provide support. Even older people with dementia who come under the category of homeless can still maintain their independent lifestyle if a network of supports is established. This network could consist of friends, volunteers and local community services.

Consequently when a person is diagnosed with dementia a full assessment needs to be undertaken not only of the individual but also of the person’s whole ecosystem, that is the person’s physical environment, social environment, interests and activities and the service system available to them. Once this occurs a case manager could link the person into these supports. In this approach the role of assessment and case manager is absolutely vital.

4. Help people with dementia and their carers plan for their futures, including organising their financial and legal affairs and preparing for longer term or more intensive care requirements.

Our experience, which is supported by a number of studies including the recent report by Alzheimer’s Australia NSW “Why don’t people plan for their future care”, indicates that major barriers to people with dementia and their carers planning for the future are:

- Not knowing where to access information
- Not understanding the information that is available
- Not receiving support or guidance from GPs and other health professionals.
- Not seeing any value in planning ahead

Many people are reluctant to plan for the future as they do not want to contemplate getting old and what that means. Much of this is associated with the whole stigma of ageism and seeing older people as non-functional and a burden to society. Consequently it is only when a crisis occurs, as for example when a person is diagnosed with dementia, do people start to think about what will happen in the future. However any future planning is dependent upon the information, support and guidance people receive, and when this is not obtained, which is not unusual, then proper planning for the future does not occur.

Too often information about dementia is given at the same time of the diagnosis, but we have found that people often cannot take in this information as they are still shocked by the diagnosis. As a result health professionals need to ensure another consultation is arranged where they can sit with the person with dementia and family and provide the necessary information about dementia. An excellent model for this approach is that of the Cognitive and Dementia Memory Services (CADMS) where a follow up meeting is arranged approximately four weeks after the initial diagnosis to discuss future planning.

Also information given to people following a diagnosis of dementia is often sketchy and may just consist of handing out a brochure. One way to address this issue would be the creation of a new Medicare Benefits Scheme number to remunerate health professionals for providing full information after a diagnosis is made.

Our services have reported that people with dementia and their carers have said that they not only need the initial information but also access to information and support on an ongoing basis. By this our clients mean access to information and support when they require it. For example, after the initial diagnosis often the person with dementia continues to function reasonably well. However there comes a time when there are real problems with their functioning and at this is when families may start to think about how the person with dementia can continue to make decisions about their personal affairs, including their health and finances. At this stage the person with dementia (if capable) and families often seek information on areas such as guardianship, enduring power of attorney and advance care plans, and often health professional are not equipped to provide this information.

This again points to the need for a case manager, who may have initially assisted the family and person with dementia, to continually to be available to provide information when it is required, which is usually because a crisis point has been reached. This case manager could provide relevant advice on guardianships and enduring power of attorney, and could refer the people to a service which specialises in developing advanced care plans. In this regard it is hoped that some of the new funding for tackling dementia as announced as part of the Aged Care Reforms can be utilised to ensure people with dementia and their families do get the ongoing support of a case manager.

We believe some of these problems could be overcome if people were told in the early stages of dementia that this disease is terminal. If people were aware of the disease’s progression and terminal nature then it is likely they would be motivated to plan for the future and make arrangement dealing with financial, legal and medical matters.

5. Increase opportunities for continued social engagement and community participation for people with dementia

Often when people are admitted into residential aged care facilities they lose contact with their local community and this is even more so for people with dementia. One initiative that Benetas found to be particularly effective was a program operated in conjunction with the National Gallery of Victoria. In this program residents with dementia from some of our aged care facilities made regular visits to the National Gallery. Staff at the Gallery received some training in regards to dementia and they showed the people with dementia around parts of the Gallery. In addition the people with dementia communicated with other visitors to the Gallery. Consequently this group were given real opportunities for community participation, and the result indicated the participating people received real benefits from this program.

Another project we are about to commence is a choir for people with dementia which will also include students from a nearby secondary college. This project is aimed at not only giving people with dementia a pleasant experience through singing, but also enable them to connect with young people. The project will be fully evaluated and the expectation is that the people with dementia will benefit from the singing and particularly so from engaging with a younger generation. Also it is expected that the younger people will gain a better understanding of dementia and become more accepting of people suffering from this disease. This project will be of special interest as it is expected to become self-sustaining as the only extra cost and resource required will be the music therapist.

The above projects indicate that measures can be undertaken to promote community engagement for people with dementia in residential aged care, some with minimal costs. However most programs of this type will require some funding and it is hoped that some of the additional funding announced in the Aged Care Reforms will be available to commence these types of programs.

Also it would be of benefit if these programs could be publicised and the establishment of a portal, or clearing house, on projects assisting people with dementia to connect with their communities would be a worthwhile initiative.

6. Conclusion

From our experience, people with dementia and their families, require an assessment very early in their journey, being linked to appropriate support services and having an individual case manager who can provide guidance, information, support and referrals when required.

We have found that a real barrier to early diagnosis is the stigma attached to the disease. Consequently a national public education program needs to be undertaken and projects which focus on linking different generations with people with dementia need to be funded.

Also, people with dementia and their carers need to be given opportunities to continue their social engagements and not become socially isolated. They need access to activities of interest, connection with people in the community and continued engagement with organisations in which they participated prior to having dementia. This applies particularly to people in residential aged care where there is a high risk of social exclusion for people with dementia.