

Fronditha Care

Response to Parliamentary inquiry into dementia early diagnosis and intervention

Introduction

Fronditha Care is pleased to submit its views to the Parliamentary inquiry into dementia early intervention and intervention. Our response offers some general comments, and addresses the key points for consideration in the House of Representatives Committee request and uses these to provide the structure of this response.

The response that follows focuses on people from culturally and linguistically diverse backgrounds and addresses the first two of the four focus points upon which input is sought. Interspersed within these two points are elements that address more appropriately the third and fourth focus points:

- 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.

The response commences by profiling the Greece (& other overseas born) Greek-speaking population to which Fronditha Care provides residential and community based care and support services.

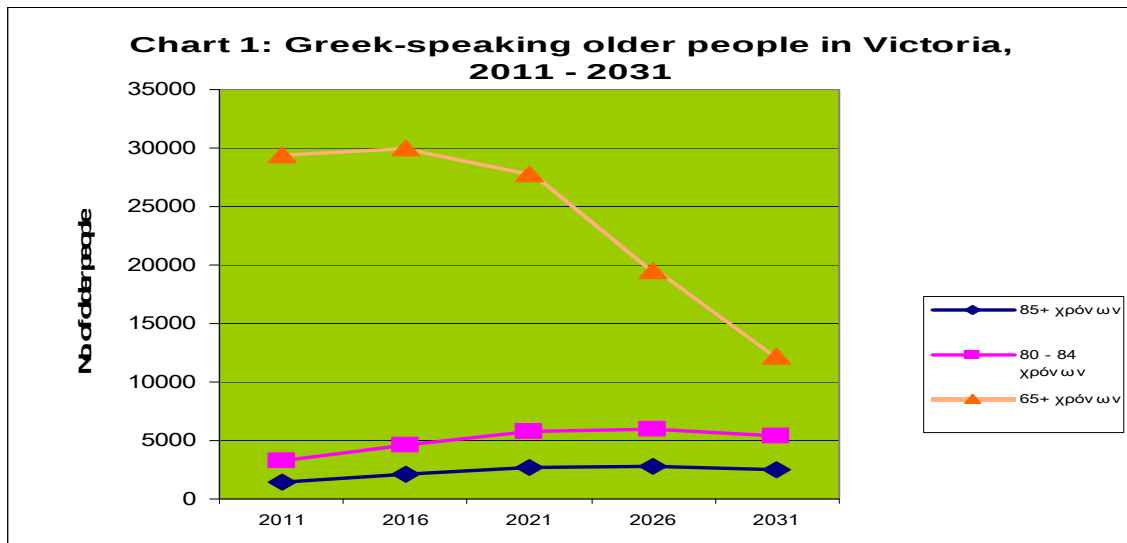
1. An ageing population

The ageing of Australia's population¹, with Greece (& other overseas born) Greek-speaking population aged 65+ years peaking in 2016, although those aged 80+ years will continue ageing at a faster rate than their Australian counterparts until 2026.

Chart 1 depicts the demand patterns for Greece (& other overseas born) Greek-speaking people living in the Melbourne metropolitan area:

- ❑ an estimated 29,438 older people of Greek-speaking background living in the Melbourne metropolitan area were aged 65 years and over in 2011
- ❑ of those, approximately 4,718 were aged 80 years and over in 2011. Based on the general rule of approximately one in four persons over 80 requiring residential aged care it amounts to a total catchment pool of around 1,180. In 2026 this is expected to increase to 2,188.

¹ Productivity Commission Inquiry Report (2011). *Caring for older Australians*. Canberra: Australian Government, Vol. 1, page v.



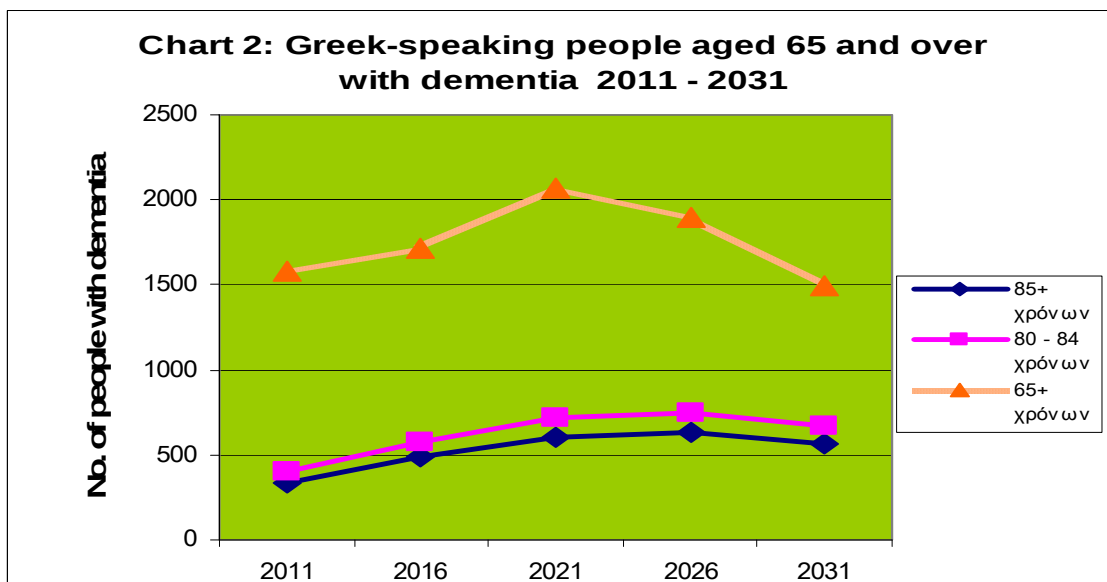
Dementia

Chart 2 and Appendix 1 show that in 2011 an estimated 1580 people aged 65 and over had dementia within Victoria's Greek community and these are expected to increase to 2066 by 2021. The majority of these people require residential care or extended care at home.

Currently, Fronditha Care provides residential care to 161 persons with dementia, even though it only has 30 dementia specific beds.

If we take into account the combined number of dementia-specific beds offered by Fronditha Care and St. Basil's run by the Greek Orthodox Church of Melbourne and Victoria, then there are 54 beds to meet the needs of an estimated 1580 older people with dementia within Victoria's Greek community.

The above indicate that the services offered by Fronditha Care and St. Basil's are insufficient and will continue to be insufficient to meet the demand for dementia specific care.



Froniditha Care is aware of changing patterns of disease among the aged, including the increasing incidence of chronic disease such as dementia, severe arthritis and serious visual and hearing impairments, and the costs associated with care. Providing linguistically appropriate care to CALD people with dementia is particularly important as they often experience language reversion and forget their acquired English due to a cognitive impairment (Productivity Commission, 2011:48).

Given Froniditha Care's existing waiting list for both residential aged care and community services, and its limited number of beds and CACPs packages, the possibility of newly assessed older people receiving services from Froniditha Care is becoming increasingly remote. Yet a large number of older people from these communities prefer to wait in the hope they would age in an environment where their linguistic and cultural needs will be catered for. Others accept services from mainstream service providers as a temporary measure, while applying to transfer to Froniditha Care aged care facilities or CACPs when a suitable vacancy occurs. This indicates a preference to be with a provider that is responsive to their linguistic and cultural needs.

An increasing number of CALD older people

The increasing number of people from diverse cultural and linguistic backgrounds and the diminishing support within the existing service system for appropriate service models for CALD older people continue to build pressure within those communities. This system has generally failed to acknowledge the profound importance of cultural identity and language in providing care for CALD older people². Culturally-specific organisations offer bilingual staff. This improves the accuracy of communication and efficiencies regarding assessment, collection of information, appropriate and meaningful service responses and cultural sensitivity. Involving 'third parties', e.g., interpreters, for initial needs gathering can often be disengaging

Table 2 indicates, expanding Froniditha Care's catchment to other communities shaped by post war immigration, such as Italian-speaking, would increase the pool of potential clients in the short-term but not change the longer-term demographic realities, unless second generation Australian born Italian-speaking or for that matter, Serbian or other cultural groups display a preference for Italian or Serbian-specific aged care facilities.

Froniditha Care is currently considering these issues and with 2011 Census statistics made available this year; it is an opportune time to review data pertaining to other potentially complimentary communities, such as Southern Europeans.

Table 2: Projections³ of selected CALD populations aged 65 years and over, 2011 – 2021

Language spoken at home	Year				
	2001	2006	2011	2016	2021
Italian	39129	43787	44371	44766	43483
Greek	19194	25786	30714	32896	32722
Maltese	4523	5537	6841	8196	8783
Macedonian	3318	4998	6957	10002	12917
Spanish	1762	2440	3541	4813	5775

² Outcomes Plus (April 2011). *The 2011 Froniditha Board Strategic Planning Workshop*. Document developed for Froniditha Care. See Background Paper, pages 3–5 in this document.

³ Howe, A. (2003). *Cultural diversity, ageing & HACC: trends in Victoria in the next 15 years*. Report commissioned by the Aged Care Branch, Department of Human Services Victoria, page 53.

French	1735	1960	2261	2776	3266
Serbian	1465	2177	2708	3477	4169

Bearing in mind that Greece (and other overseas born) Greek-speaking older people, in particular those aged 80 years and over, will peak in 2026, and being cognisant that upgraded or new facilities have a life span of 25 to 40 years, Fronditha Care will be in the fortunate position of seeing the vision and mission of its founding members successfully accomplished by 2031. Adding to these the recommendations of the Productivity Commission, Fronditha Care has commenced the process of:

- determining the size in residential beds and community-based services that it will require for the next 20 years to continue providing high quality and culturally appropriate care and support to older people of Greek-speaking background, in particular to those experiencing dementia and other neuro-degenerative conditions
- reviewing ABS Census 2011 data relating to other Southern European communities (will complete this once Census data becomes available towards the second half of this year), i.e., Italian, Serbian, including:
 - number, age and geographic location of CALD older people in Victoria in five years cohorts 65-69 years; 70-74 years; 75-79 years; 80-84 years; 85-89 years; and 90+ years
 - sources and level of income of CALD older people
 - long term projections to 2050 for CALD ancestries
 - number and projected number of people with dementia and other chronic diseases within the CALD communities in Victoria 2011 to 2050.

At this stage we have been unable to ascertain detailed statistics on the Italian and other CALD speaking elders, but we are committed to develop that data.

- establishing a timeline for replicating its successful Newcastle multicultural model in Victoria. Establishing such a timeline, will allow it to pursue a seamless transition to a multicultural orientation in Victoria taking advantage of the opportunities likely to present should the Commonwealth Government adopt the recommendations of the Productivity Commission
- developing a range of culturally appropriate aged service delivery models to ensure CALD older people age well, age healthy irrespective of language, culture or location
- assisting mainstream and smaller ethno-specific aged care providers to support changes in their current model configuration towards more inclusive multi-cultural aged care models
- evaluate these multi-cultural aged care models to ensure their continuous improvement, viability and appeal to CALD older people.

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

As seen above, the population of Greece (and other overseas born) Greek-speaking people aged 65 years and over in Victoria are increasing and it is recognised that often the diagnosis of dementia of people from a culturally and linguistically diverse background can be made later than people born in Australia. Yet early diagnosis allows

a person with dementia, their family and carers to receive help in understanding and adjusting to the diagnosis and prepare for the future in an appropriate way. This might include making legal and financial arrangements, changes to living arrangements, and finding out about aids and services that will enhance the quality of life for the person with dementia and their family and friends.

Early diagnosis can allow the individual to have an active role in decision-making and planning for the future, while families can educate themselves about the disease and learn effective ways of interaction with the person with dementia.

Functional assessment enables identification of strategies to reduce risks, maximise independence in daily tasks and identify necessary modifications of the home environment to maximise function. Additionally, a diagnosis of dementia can facilitate access to a number of medications that may reduce the symptoms of dementia—for people in the mild or moderate stages of dementia, medications may improve clear thinking and the ability to carry out daily tasks, as well as reducing hallucinations and delusions.

Fronitha Care has concerns about the time it takes to get a diagnosis and also that individuals are often misdiagnosed with depression. There is a need to develop and/or use culturally and linguistically appropriate assessment tools, such as the Roland University Dementia Assessment Scale (RUDAS).

While Fronitha Care is making every effort to inform the Greek Community, fragmentation within the Aged Care sector makes it difficult for families and carers to understand the aged care system. Greece (and other overseas born) Greek-speaking people have a strong preference for information to be provided face-to-face so that they could seek clarifications on the spot. For this group of people, accessing information in their own language is still proving to be a challenge. Our clients tell us that they prefer to access information from a central point in their own language.

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

Analysis undertaken by Fronitha Care indicates that an estimated 1,580 people within Victoria's Greek community have dementia (please see Appendix 1). Assessment of individual needs and the high number of referrals received for both dementia-specific residential and community care and support programs demonstrate that many of the 1580 people with dementia, their carers and other family members, including their children and grandchildren may be missing out on information, care and support. Often carers and their families are homebound and isolated from supportive networks and services able to provide information, link them with others in similar circumstances and alleviate social isolation.

Fronitha Care proposes to increase opportunities for continued social engagement and community participation for people with dementia through the delivery of the following new programs from 2012 to 2015:

1. Life stories

To provide opportunities for people with dementia to have their life story developed, specifically enhancing the experience of people with dementia from a CALD background. Life stories can be created through writing, painting, patchwork, collection of meaningful photographs or other items of value, displays etc. Through this

program, Fronditha Care will produce a comprehensive life story kit. These life stories will provide a personal history of each person promoting self-worth.

The life stories kit will be shared with mainstream providers so that they can implement similar programs with their clients of Greek-speaking background and create further opportunities for elders with dementia to participate in meaningful activities. The life stories will provide insight into the experience of people with dementia within a Greek context, enabling mainstream providers to enhance their cross-cultural awareness and understanding of their clients.

Life stories are a creative way of sharing the journey of dementia within the Greek community, and are easily related through narrative story telling (For benefits associated with the creation of life stories please see *Appendix 2, Section 1*).

2. Production of a story book

The need to bring up communication issues, such as why grandma does not remember my name, or why grandpa is not able to communicate with me anymore is integral to responding appropriately to the challenges of dementia. It is also important that information is shared with all generations, as dementia continues to be taboo within the Greek community. Fronditha Care is aware that if all generations can understand dementia better, then fear of the condition may be dissipated and, with that, denial and stigma may be lessened.

Fronditha Care proposes to develop a story book, aimed at children, to bridge the gap of understanding and facilitate effective communication between grandchildren and their grandparents or relatives who may have dementia. The story line will be culturally sensitive and responsive to the needs of the Greek community, incorporating images and content that is familiar and easily related to.

3. Carer / family education program

Fronditha Care proposes to pilot a tailored carer and family education program for older Greek-speaking people with memory loss in Melbourne's Southern Region facilitated by the project coordinator. The pilot program will be evaluated and then replicated in other metropolitan regions of Melbourne.

This program will be based on Alzheimer's Victoria Living with Memory Loss Program and Memory Lane Cafés, and after careful analysis, modified to suit the specific needs of the Greek community, acknowledging that generally within this community people are diagnosed at a later stage of their dementia. The type of approach and information will therefore need to address this fact and at the same time give the carer and the person with dementia an opportunity to receive valuable information, support and connectedness within the service system. The model can then be modified and replicated by other CALD communities.

It is envisaged that at each session two groups will meet concurrently, one for people with dementia, and one for their family members. The program will consist of seven sessions of one and a half hours run on a fortnightly basis. Groups will be limited to ten participants (For more details about these sessions and their benefit, please see *Appendix 2, Section 2*).

4. Telelink

The project coordinator will initially facilitate the development of Telelink carer groups in all four Melbourne metropolitan regions. This will involve promoting the program and recruiting participants to later providing information, supporting members, managing group dynamics and offering technical support. It is envisaged that through this process suitable carers will be identified and be trained to later facilitate the Telelink group on a voluntary basis. This is particularly important whereby carers may no longer be in their caring role and offers an opportunity to undertake a valuable and rewarding volunteer work (Please see *Appendix 2 section 3* about the role of carers as group facilitators).

This initiative acknowledges that carers are time poor and often are house bound due to their caring role. Telelink carer support groups provide an avenue for creating informal networks, receiving helpful information and having the opportunity to be heard by people in similar circumstances.

5. Dementia education program

Currently, there is a great deal of stigma associated with dementia, resulting in people being marginalised and isolated within the Greek community and sometimes even from family members. Stigma and the continuum from initial diagnosis to losing functional abilities, such as mobility, living skills and eventually memory, are likely to cause carers and families considerable hardship.

While there is no simple way of overcoming these hardships, Fronditha Care proposes to produce a DVD to present to members of the Greek community with information about dementia that will assist them to understand the complex and changeable emotions carers and families of people with dementia experience. These emotions may include distress, frustration, guilt, grief and loss, exhaustion, annoyance and anger.

The DVD is expected to take two years to research and produce. Apart from being used to educate members of the Greek community, the DVD will also be used to educate mainstream agencies on how to provide sensitive and culturally appropriate care to people with dementia from Greek background. The DVD will be uploaded on Fronditha's Greek Care website for free download.

6. Promoting healthy and active ageing for carers

The word 'carer' is an unfamiliar term in the Greek context. Instead, carers see their role as something that 'they just do' for their family member. Embedded within this is the cultural expectation. Similarly, the term 'self-care' is a foreign concept. It is recognised that providing balance and quality time between the carer and person with dementia enriches the caregiving experience.

Fronditha Care proposes to deliver a culturally appropriate education program, specifically for carers, through a range of media, accessed by a large number of Greek older people throughout Australia, to promote self-care and healthy and active ageing.

Potentially, the six proposed programs are expected to reach over 50,000 of Victoria's Greece-born people⁴. Information will spread quickly as the Greek media enjoys a broad following. 'Word of mouth' is also a strong communication tool for disseminating information in the community.

4. Fronditha Care

Fronditha Care is an established aged care service provider offering a range of services to older people from culturally and linguistically diverse backgrounds (CALD). Programs include:

- Information and referral
- CACP across Melbourne's Metropolitan regions
- High & low residential aged care in all four Melbourne Metropolitan regions and Newcastle in NSW
- Provision of cultural and linguistic information to mainstream service providers through the Greek Care Website
- HACC services including the Supported Access Pilot Project, Planned Activity Groups and Volunteer program
- Host Home Respite
- Social housing.

The following principles underpin Fronditha Care's service provision:

- Locate services close to the communities they serve
- Provide a range of services to meet the varying needs of financially disadvantaged CALD elders
- Provide continuity of care as elders frailty increases and needs change
- Provide culturally responsive services
- Pursue partnerships with mainstream service providers to enhance their capacity to provide culturally responsive services. For example, medication management with the National Prescribing Service and council on the Ageing Victoria, Host Home and Carer Support Groups with the United Care Community Options and the Southern Commonwealth Respite and Care Link Centre, as well as an activity group for CACP clients in Melbourne's Northern region with Merri Community Health Service
- Ensure the long-term financial viability of the organisation.

Conclusion

Fronditha Care believes there is a looming crisis in meeting the care needs of Greek and Italian-speaking elders and more importantly of smaller CALD communities bereft of any infrastructure and resources to respond to those needs and the redress of the crisis must demand urgent attention by the Commonwealth Government.

⁴ ABS (2007). *2006 Census – Basic Community Profiles Victoria*. Canberra, ABS, Cat. No. 2001.0.

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Appendix 1

Projections: Victoria's Australian Greek-speaking elders* aged 65 years and over, 2011–2031⁵

Year	2011	2016	2021	2026	2031
80–84 years % increase since 2011	3,227	4,605 42.7	5,745 78.0	5,985 85.5	5,364 66.2
85+ years % increase since 2011	1,490	2,128 42.8	2,656 78.3	2,765 85.6	2,478 66.3
80+ years % increase since 2011	4,718	6,733 42.8	8,404 78.1	8,750 85.5	7,842 66.2
65+ Total % increase since 2011#	29,438	30,048 2.1	27,762 – 5.7	19,516 – 33.7	12,185 – 58.6
Projections: Victoria's Greek-speaking elders with dementia aged 80–84 and 85+ years (see Appendix 1)					
80–84 years % increase since 2011	403	576 42.9	716 77.7	748 85.6	670 66.3
85+ years % increase since 2011	339	484 42.8	604 78.2	629 85.6	564 66.4
80+ years % increase since 2011	741	1060 43.1	1320 78.1	1377 85.8	1234 66.5
65+ years % increase since 2011	1580	1717 8.7	2066 30.8	1897 20.1	1499 – 5.1
Number of Greek speaking elders with dementia⁶ using Fronditha Care services					
65+ years	161 ⁷				

* Denotes that these Greek-speaking people are born in Greece or other overseas countries, such as Cyprus or Turkey.

Denotes that the percentage increase of the Greece (& other overseas born) Greek-speaking 65+ years population is peaking up in 2016 and then declining significantly by 2031.

⁵ Constantine Tsingas (1998), *Forty Years Later: A Demographic and Need Analysis Study of Victoria's Australian Greek elders*. Melbourne, Fronditha Care, Table 3.1:17). With the 2011 Census being released sometime this year, it is a long overdue opportune time to update these projections and undertake a wide ranging analysis of Greece born (and other overseas born Greek-speaking people).

⁶ Dementia incorporates the following conditions: dementia, Alzheimer's, cognitive impairment, cognitive changes, mild cognitive impairment, cognitive decline, early cognitive impairment, disorientation, amnesia, confusion, memory impairment.

⁷ In Fronditha Care aged care facilities

APPENDIX 2

1. Promoting person-centred care for people with dementia and their carers

The use of life story work contributes to:

- the reduction in the use of medication, improved physical health and quality of life.
- the healing process for carers of people with dementia
- helping staff, volunteers and mainstream providers see every person as an individual, looking beyond their dementia
- the intervention process which underscores a person-centred approach to the care of people with dementia, by allowing conversations to be initiated
- allowing family carers to uphold their relatives' personhood and reflect on their journey with the person with dementia
- the discovery of the rich and complex patterns of people's lives prior to developing dementia
- enabling the voice of the person with dementia to be heard, verbally and non-verbally.

2. Carer / Family Education program

To give each member the opportunity to:

- tell their story of memory loss
- reflect on the impact of their diagnosis
- develop an understanding of the importance of self-care
- enhance their skills for communicating with others
- learn techniques for problem solving
- extend their knowledge about legal and financial issues.

According to Alzheimer's Australia⁸ this type of program can:

- reduce the sense of isolation, distress and depression
- increase the self-esteem of people with or caring for someone with dementia
- increase knowledge of local services, and
- gain positive perceptions of dementia.

3. Telelink

The role of carers as group facilitators will be to:

- guide the session and provide support to participants
- encourage discussion and sharing between group members
- keep the balance between the needs of each individual and the needs of the group
- remain sensitive and mindful of the need for privacy, and
- provide technical support.

⁸ Alzheimer's Australia Victoria: Living with Memory Loss

APPENDIX 3: Estimated number of people with dementia within Victoria's Greek community

Age Cohort						Estimated Prevalence rate of dementia in Australia 2010 ⁹ (Percentage of population)	Estimated number of people with dementia				
	2011 ¹⁰	2016	2021	2026	2031		2011	2016	2021	2026	2031
65–69 Years											
• Male	4140	3075	2394			1.7	70.4	52.3	42.5		
• Female	5042	4190	3147			1.3	65.6	54.5	40.9		
• Persons	9182	7265	5541			1.5	136.0	107.0	83.4		
70–74 Years											
• Male	4277	3647	2709	2109		3.5	149.7	127.7	94.8	73.8	
• Female	4720	4734	3934	2955		3.3	155.7	156.2	130.0	97.5	
• Persons	8997	8381	6643	5064		3.4	305.4	184.0	224.8	171.3	
75–79 Years											
• Male	3141	3445	2938	2182	1699	5.8	182.2	199.8	170.4	126.6	98.5
• Female	3400	4224	4236	3520	2644	6.3	214.2	166.1	266.9	221.8	166.6
• Persons	6541	7669	7174	5702	4343	6.05	396.4	365.9	437.3	348.4	265.1
80–84 Years											
• Male						12.1					
• Female						12.9					
• Persons	3227.43 ¹¹	4605 ¹²	5748	5985	5364	12.5	403.4	576	716	748	670
85+ Years											
• Male						21.1					
• Female						24.4					
• Persons	1490.57 ¹³	2128	2656	2765	2478	22.75 ¹⁴	339.1	484	604	629	564
65+ Total											
• Male	13554	12886	11172	7188	4011		1580	1717	2066	1897	1499

⁹ Access Economics. (July 2010). *Caring places: planning for aged care and dementia 2010–2050*, Volume 1, Chart 1.1 page 12, Alzheimer's Australia.

¹⁰ Tsingas C. (1998). *Forty Years Later: A demographic and needs analysis study of Victoria's Australian Greek Elders*, Table 3.1, page 17. Melbourne, Fronditha Care.

¹¹ According to the ABS 2006 Census the total number of persons of Greek ancestry was 1490.57 (Please see footnote 4). This figure was subtracted from the total number of persons aged 80+ years which was 4718 to find the total number of persons aged 80–84 years. (Please see Tsingas (1998) Table 3.1, i.e., 4718 – 1490.57 = 3227.43 persons aged 80–84 years).

¹² To calculate this figure, the 2011 total of those 80+ years (i.e., 4718) and the 2011 total of those 80–84 years (i.e., 3227.43) were used to ascertain the percentage total for those aged 80–84 years and those aged 85+ (i.e., $3227.43 \times 100 \div 4718 = 68.4$ percent) and (i.e., $1490.57 \times 100 \div 4718 = 31.6$ percent)

¹³ The following ABS sources were used to calculate this figure: ABS (2007). *2006 Census – Time Series Profile Australia*, Canberra, ABS, Cat. No. 2003.0, T12 (c), and ABS (2007) *2006 Census – Basic Community Profiles Victoria* (STE 2). Canberra, ABS. Cat. No. 2001.0 Table B08 and B13. Table T12(c) indicates that the total number of people with affiliation to the Eastern Orthodox religion in Australia were 544,161 and those aged 85 and over were 5170. Table B13 indicates that the total number of people affiliated with the Eastern Orthodox Religion in Victoria were 224,037. Victoria's population represents 41.2% of those affiliated with the Eastern Orthodox Religion in Australia (i.e., $100 \times 224,037 \div 544,162 = 41.17$). Victoria's total number of people aged 85+ years affiliated with the Eastern Orthodox religion in Victoria were 2128.5 (i.e., $5170 \times 41.17 \div 100 = 2128.48$). Table B08 indicates that Victoria's population of Greek ancestry were 156,902. This represents 70% of Victoria's population affiliated with the Eastern Orthodox Religion (i.e. $156,902 \times 100 \div 224,037 = 70.03$), and there are 1490.6 people aged 85+ years who have Greek ancestry (i.e. $2128.48 \times 70.03 \div 100 = 1490.6$).

¹⁴ The combined prevalence rate of those aged 85–89 years old ($21.1 + 24.4 = 45.5 \div 2 = 22.75$) was used to ascertain the number of people with dementia aged 85+ years ($1490.57 \times 22.75 \div 100 = 339.1$) (Based on the Access Economics prevalence rate as per Chart 1.1, in Footnote 2 above).

• Female	15884	17162	16590	12328	8174						
• Persons	29,438	30048	27762	19516	12185						