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Macedonian Australian Welfare
Association of Sydney Inc.

PERCEPTIONS OF DEMENTIA IN THE MACEDONIAN COMMUNITY



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References

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people finding out” about their problem, which can bring “*shame to their family*”. If they admit to having Dementia, or other mental health problems/issues with their nerves, or feeling anxious/ agitated/ tired/ having fear of something or have cold sweats or heart palpation. Some people described Dementia as something that come from other, “*powerful forces*”, or “*curse*”, and therefore cannot be treated by a doctor*. (Macedonian Mental Health Project Report, 2003).

Some attitudes towards Dementia

Opinions of community members directly affected by dementia;
When you have Dementia, or other kind of mental illness, Macedonians lose all respect for you. They don't accept you anymore; they don't even give you a chance. It is their mentality. When one finds out the word starts spreading and then the whole family suffers from shame, especially the children. Macedonian people can be very cruel!(Information was given from female carer aged 60 yrs).

“They should only share this information with family members and friends who are strong enough and smart enough to understand. Not everyone should know... People in the family or friends they can trust and people who can take this calmly...People who will not be very disturbed with the news. Don't tell people who are weak and can not handle the truth or people who will ridicule them later on”. (Information was given from female carer 65yrs).

“People or friends would start avoiding them. Many people are afraid to associate with people with Dementia. They would no know how to communicate with people like them” (female community member 50-55yrs).

“Yes they would avoid the person and gossip especially if he/she is Macedonian-everyone will find out” (male community member 65yrs).

Introduction

Levels of understanding on Dementia issues vary amongst the Macedonian Community. Dementia is still a highly stigmatised and misunderstood illness amongst older generations of Macedonian people. There are a number of factors that influence their perception such as: culture, religion, and lifestyle.

The information provided in this booklet intends to increase the awareness of aged care providers as well as the wider community on the different aspects of Dementia and how the Macedonian culture perceives Dementia.

The factual information contained here, have been directly received from survey's, conducted with the Macedonian Carers Support Group in Rockdale. In addition, this information has also been obtained through recent reviews of case management notes of individuals who care for people with Dementia.

Dementia and the Macedonian Culture

In the Macedonian culture older people are highly respected and older family members are usually involved in the decision making process and are often expected to mediate disagreements. Sons are often encouraged and expected to live with their parents after marriage and provide assistance with the aged care needs as they arise. Most older people expect to live with the family until the end of their lives. Therefore, extended families are the norm. Traditionally, families have a patriarchal social structure, however during decision making processes the whole family plays an important role in time of hardship or illness.

Macedonian Beliefs

The Macedonian religion is Christian Orthodox and it has influenced people in fundamental ways. Often people express a fatalistic approach to health: *“If it is written it is written- you can not escape from what ever is written”*, or *“it was meant to happen”* and therefore is very little that can be done.

Macedonian Lifestyle and Dementia

Commonly, the lifestyle of the Macedonian community is one of liberal consumption of alcohol and fatty foods with little understanding that these lifestyle choices may cause immeasurable harm.

The Macedonian community is ageing faster than the general community and it is expected to have a similar percentage of people with Dementia as that of the general population. There is a high incidence of Alcoholism, Stroke and Heart attack within the Macedonian community; this group is unaware of the relationship between these health issues and Dementia. There is a lack of understanding of the causal relationship between Alcoholism, Stroke, and Heart attack to Dementia (NSW Transcultural Aged Care Service, 2003).

Understanding Dementia in the Macedonian Community

Dementia, along with other mental illnesses, is a highly stigmatised and misunderstood illness for older Macedonian people. There is no word meaning Dementia in the Macedonian language, which creates even more confusion. It is not openly discussed within the community and often family members tend to ignore or minimise the problem or try to deal with in their own way without involving health professionals. Members of the community usually see the illness as weakness of character or a *“family shame”* resulting in a *“collective loss of face”* for the extended family

Clients and cares often described Dementia in personal term as *“living in a world of one’s own”*, or *“feeling upset – hopeless”*, while community members often described Dementia in more impersonal or distant terms such as *“sclerosis”*, or *“older people illness”*. Common descriptions of Dementia by community members are that: *“Big shame for the whole family, not for the patient only. Your life will never be the same. Life with the mask which is not yours”, and similar.*

Professional’s help is often sought when other avenues have been exhausted and the crisis in the family becomes intolerable. People tend to seek help through a hospital rather than from a GP or community based mental health services, as this was the practice in Macedonia. Most Macedonian people prefer treatments often in the form of injections, as was commonly practiced in Macedonia many years ago, rather than ongoing counselling or psychological interventions.

The older members of the community though that people of their generation would hide their mental health problem, including Dementia, and would only discuss it within their immediate family. Reasons for this include the *“fear of other*