Content of this presentation

- The dementia concept
- The Maltese situation (past and present)
- The National Dementia Strategy (future)
What is dementia?

‘Dementia refers to a group of brain diseases associated with behavioural, cognitive and personality changes. It presents itself as impairment in memory, abstract thinking, impaired judgement and other disturbances that are of such a severity that they interfere with work and social activities’
Dementia

- Various types – most common is Alzheimer’s disease
- Characterised by considerable brain death
- Mostly associated with the elderly – age is the most important risk factor
- Is responsible for more years lived with disability in people older than 60 years (11.2%) compared to stroke (9.5%), cardiovascular disease (5%) or all forms of cancer (2.4%) – WHO data
- Is expensive
- Is on the increase
New concept?

‘My sovereign master, old age is here. Senility has descended on me…my spirit is forgetful and I can no longer remember yesterday’

Maxims of Ptah Hoty, 9th Century BC, Egypt

4th Century BC, Hippocrates: ‘Dementia a consequence of ageing’

2nd Century BC, Cicero: ‘The senile folly’

1st Century AD, Celsus: ‘Dementia defined as out of one’s mind’
‘Zmagat’

- Mentally insane
- Crazy
- Mentally deficient

Social rejection
Shame, isolation

Person with dementia

Caregiver
Reasons:

- Closed society – everyone knows everybody
- Lack of knowledge – ‘so different’, ‘fear’
- Lack of facilities
- Religion – ‘act of God’
- Stigma, taboo
- Discrimination against patient and family
September 2004 – Malta Dementia Society

What were the objectives?

Main: Raising awareness on dementia (educate)
Others: Promote the best method of care, training

How?

By bringing together all the stakeholders – policy makers, professionals, patients and carers
Malta Dementia Society

What were the problems?

Main: Financial (non-governmental, non-profit organisation)

Others: resistance to change (nobody knows you)
Situation in Malta

Estimated prevalence of dementia in the Maltese Islands

Stephen Abela, Julian Mamo, Carmelo Aquilina, Charles Scerri

Abstract
Dementia is a serious, common, world-wide neurodegenerative disease associated with severe loss of cortical brain. It is a major predictor of morbidity and mortality in the elderly costing the health services more than cardiovascular disease and cancer put together. Recent studies have also suggested that the global prevalence of dementia would double every twenty years and should reach approximately 82 million cases by the year 2040. Using EURODEM data, we report that the estimated number of individuals with dementia in the Maltese islands is 4,072. This figure is expected to almost double by the year 2055. We discuss the implications of the forecast increase in the number of people with dementia for Malta’s health services and society.

Introduction
Dementia is a clinical term referring to a group of brain diseases that result in the progressive deterioration of cognitive functions. Dementia usually presents itself as an impairment in short- and long-term memory associated with impairment in abstract thinking, impaired judgment and other disturbances that are of such severity that they interfere with work and social activities. As the disease progresses, the person with dementia will need increasing help and support in performing everyday tasks. Several diseases are known to cause dementia. Alzheimer’s Disease accounts for 50-60% of cases, while Vascular Dementia and Lewy Body Disease account for a further 15-20% each. Other disorders associated with this disease process include fronto-temporal dementia and Parkinson’s Disease. According to the 2003 World Health Report by the World Health Organization (WHO), dementia contributed to 11.2% of years lived with disability in people aged 60 years and over - much more than cardiovascular disease (5%) and all forms of cancer (2.4%). This is a significant demand on family and informal carers as the majority of care for people with dementia is provided at home.

Alzheimer Disease International and Alzheimer Europe have been campaigning for years to make dementia a public health priority in view of the increasing number of people diagnosed with dementia worldwide and the financial implications of managing the consequences of this disabling condition. People

Key words
Dementia, Malta, prevalence, EURODEM
Results

1. A progressive increase in the elderly population

Malta Medical Journal, 19(2), 2007
2. Decrease in old-age dependency ratio

![Diagram showing decrease in old-age dependency ratio from 2005 to 2050. The ratio changes from 1:5.2 in 2005 to 1:2.9 in 2025 and further to 1:2.2 in 2050.]
### 3. Increase in the number of PWD by 2050

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<th>30-59</th>
<th>60-64</th>
<th>65-69</th>
<th>70-74</th>
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<th>Total cases</th>
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<td>203</td>
<td>293</td>
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<td>444</td>
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<td>285</td>
<td>404</td>
<td>1035</td>
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<td>253</td>
<td>422</td>
<td>931</td>
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<td>414</td>
<td>970</td>
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A global challenge

- More than 7.3 million people with dementia in Europe. Will double by 2040

Population growth

- World population grew from 3 billion to 6 billion in 1999 – doubled in 40 years
- Growth will continue more slowly to 9 billion in 2042 – 50% increase in 42 years
- 6% of the world population is aged 65+
  - 17% in the UK
  - 14% in Europe
  - 3% in African countries
Malta: what is available?

(Services available for the elderly are not necessarily adequate for people with dementia)
Social Services

- Age pension (61 and over)
- Carer pension*
- Disability pension*
- Invalidity pension*

* no figures for people with dementia or their carers applying for these services
Department for the Elderly

- Day Centres (mainly for “socialising”)
- Home Care Help
- Incontinence Service
- Kartanzjan
- Meals on Wheels
- Handyman Service
- Hospitals for the elderly

*These services cater for all the elderly
* dementia wards
Homes

- Church Nursing Homes
- Private Nursing Homes
- Other Homes

None designed for dementia care
Activity Centre for people with dementia

- Launched in July 2007
- Staff trained in dementia care
- Provides a safe and creative environment
- Provides respite for carers
- Response is excellent
National Dementia Strategy Group

- Launch: May 2009 (following the Paris Dementia Conference in October 2008)
- **Objective:** Develop a strategic plan to improve dementia care in Malta
- Three areas: Current situation, consultation process, final recommendations and report
- Other countries working on a Plan: UK, Norway, France, Scotland, Germany
Current Situation Analysis Results

1. Lack of awareness
   - General Public
   - Healthcare professionals

   Awareness will improve early diagnosis and reduce stigma

A 5 year delay in the onset of AD will decrease AD prevalence by 50%
Dementia: Rights and needs

The Malta Dementia Society

Dementia is a group of brain disorders that is characterized by a decline in mental abilities severe enough to interfere significantly with independence of daily living. Due to the nature of the condition, much remains to be done in the area of disease management and the development of appropriate models of long-term care.

Extensive exploration of the possible risk factors, which has largely focused on Alzheimer’s disease, has been disappointing. Age, dementia in a first-degree family member, and a history of head trauma are some of the confirmed risk factors for the disease. In vascular dementia, the main risk factors identified are age, male sex, hypertension, myocardial infarction, coronary heart disease, diabetes, smoking, hyperlipidaemia, and a history of stroke.

The challenge to researchers in this field is to determine the relative importance of the factors, which could influence treatment. Moreover, the added, there was...
Current Situation Analysis Results

2. Lack of psychological support to carers and PWD

Approx. 60% of carers suffer from depression/breakdown/anxiety/guilt feelings

‘I feel obliged. I feel so guilty. I can’t get away from that. It’s terrible. I can’t even live my own life...I really wish I could run away but I can’t. I can’t even leave. She has trapped me really’

Daughter of a PWD
Current Situation Analysis Results

3. Lack of financial support

Most carers have to stop working with disease progression (most dementia patients are cared at home)

No reimbursement for anti-dementia drugs

‘the problem about the pills is that they are too much expensive..I take the lowest part of my pension you know..’
Husband of a PWD

‘about a third of my pension goes to the chemist you know..If I have a little bit of interest from the bank, because I had some money in the bank, I spend all the interest on medicine’
Wife of a PWD
Current Situation Analysis Results

4. Lack of infrastructure
No dementia homes
Most elderly homes are not dementia-friendly

5. Lack of research in dementia care
Healthcare students will be less prepared for the future
Fragmentation in academic preparation

6. Absence of community services
PWD and carers are left to fend on their own
Consultation process

I. Stakeholders

1. Education
2. Long-term care service providers
3. Professional bodies
4. Acute/intermediate care service providers
5. Community

A multidisciplinary, inter-professional approach

Disease model  →  Patient-centred care model
Consultation process

II. General Public

Website (part of the Department of Health, Elderly and Community Care)

- Information about dementia
- Information about the Strategy
- Online questionnaire (www.dementia.gov.mt)
- Other important links
Dementia is a general term that refers to a group of brain diseases characterised by severe and progressive cognitive decline that interferes with normal daily functioning. These deficits may include severe memory loss, mental confusion, language difficulties, mood variations and personality changes. It is estimated that more than 6 million people residing in EU member states have dementia. In Malta, more than 4,500 individuals have dementia, a figure that is expected to double by the next 25 years.

Alzheimer’s disease is the most common cause of dementia accounting for around 60 per cent of all dementia cases. Other forms of dementia include vascular dementia, Lewy-body dementia, fronto-temporal dementia and dementia secondary to disease.

Age is the most important risk factor in developing dementia. The condition affects about 1.5 per cent of individuals aged 65 years and doubles every four years to reach 30 per cent at 80 years. It is the major predictor of morbidity and mortality in the elderly and is associated with a significant increase in healthcare utilisation.

Click here for online Questionnaire.
or
Click here for downloadable Questionnaire (pdf) and send to:
Room 135,
Department of Pharmacy,
University of Malta,
Msida MSD 2080 MALTA

health, elderly and community care
health institutions | health promotion | elderly | public health | rehabilitation | others

Dementia

Dementia Information

National Dementia Strategy
Day Centres for Elderly
Persons
Home Care Help
Handyman
Telephone rebate
Telecare
Incontinence Service
St. Vincent de Paule
Residence
Elderly
Meals on Wheels
Kartajen
Residential Homes for the Elderly
Our Services

www.dementia.gov.mt
Consultation process

Questionnaire – Preliminary results

- Approx. 500 returns
- Lack of awareness
- Lack of knowledge especially in specific areas (palliative care, end of life issues)
- Lack of information about practical aspects
- Significant financial burden
Possible Recommendations

- Develop methods to increase awareness (↑ early diagnosis)
- ↑ Support to carers and PWD
- ↑ Education at all levels
- ↑ Technology
- ↑ Collaboration
- ↑ Community care
- No 1 Health Priority
‘Real generosity is doing something nice for someone who will never find out’