



ALZHEIMER AND THE MEDITERRANEAN REPORT 2016

OVERVIEW – CHALLENGES – PERSPECTIVES

Authors

Salomé Nicaise, Federico Palermi,
Monegasque Association for research on Alzheimer's disease
(AMPA)



ASSOCIATION MONÉGASQUE
POUR LA RECHERCHE SUR LA
MALADIE D'ALZHEIMER
AMPA



ALZHEIMER AND THE MEDITERRANEAN REPORT 2016

OVERVIEW – CHALLENGES – PERSPECTIVES

Authors

Salomé Nicaise, Federico Palermi,
Monegasque Association for research on Alzheimer's disease
(AMPA)



MONEGASQUE ASSOCIATION FOR RESEARCH ON ALZHEIMER'S DISEASE

Europa Résidence - Place des Moulins - 98000 MONACO

Tel: +377 92 16 58 88 - Fax: +377 92 16 58 81

info@ampa-monaco.com - www.ampa-monaco.com

Twitter: @AMPAAIzMonaco - **Facebook:** ampamonaco

Publishing Director: Federico Palermi

Executive editor: Salomé Nicaise

Interviews: conducted by Salomé Nicaise and Federico Palermi

Translation: Kate Williams and Serena Di Orio

Proofreading assistance: C.I.R Rozbroj

Graphic design and layout: Federall - Communication | Création graphique - www.federall.net

Impression: Graphic Service - GS Communication S.A.M - www.gsmonaco.com

All rights (reproduction, translation, adaptation) reserved for all countries.

SUMMARY

PREVALENCE	8
PUBLIC HEALTH PRIORITIES	12
LEGAL AND ETHICAL ISSUES	16
SOCIO-ECONOMIC COST	20
DIAGNOSIS	22
CARE AND SUPPORT	26
HEALTHCARE PROFESSIONALS	30
MEDICAL TREATMENTS AND PSYCHOSOCIAL INTERVENTIONS	32
RESEARCH AND PREVENTION	36
FAMILY CARERS	40
PUBLIC PERCEPTION	44



“Confronted with Alzheimer’s disease in my family, I am aware of the confusion that this illness ushers into our lives. With the Monegasque Association for research on Alzheimer’s disease (AMPA), my objective was to rally for this cause.

My first wish was to better understand the illness, by supporting and encouraging scientists on an international level. Thanks to AMPA, several renowned international medical congresses have been held in Monaco and have led to promising research.

My second wish was to increase public awareness, so that every individual feels concerned and united. Bringing this illness into the limelight will help to change the still strongly stigmatised image that our society has of people with Alzheimer’s disease and their carers.

My third wish was to bring help and support to families, who often feel helpless and unassisted. AMPA provides them with advice and useful information and finances concrete projects, such as the creation of new structures, to improve the quality of life of people with Alzheimer’s disease and related disorders.

Today, I want to pursue and amplify my support by helping Mediterranean rim countries. This is why I launched the Mediterranean Alzheimer Alliance in 2013, which brings together 17 countries. International studies have shown that in the next 20 years, the number of people with Alzheimer’s disease is set to increase tremendously, particularly in the Mediterranean region. Faced with this sudden increase, our privileged links should encourage us to work together to ensure that Alzheimer’s disease becomes a public health priority in the region.

I sincerely hope that this first report will serve as a tool to inform political decision-makers and concerned stakeholders in order to anticipate future issues for the Mediterranean region”.

Catherine Pastor
President, AMPA

The Monegasque Association for research on Alzheimer’s disease (AMPA) was established at the initiative of Michel Pastor and Dr Michel-Yves Mourou in 1990.

Since 2009, the association has been chaired by Catherine Pastor and its Vice-President Professor Alain Pesce, head of Monegasque geriatric services.

AMPA works on a national and international level to support research, encourage scientific meetings, disseminate expertise and knowledge, increase public awareness and inform and accompany people with Alzheimer’s disease and their carers.



ASSOCIATION MONÉGASQUE
POUR LA RECHERCHE SUR LA
MALADIE D’ALZHEIMER

AMPA

AMPA

Europa Résidence - Place des Moulins - 98000 MONACO

Tel: +377 92 16 58 88 - Fax: +377 92 16 58 81

info@ampa-monaco.com - www.ampa-monaco.com



ampamonaco



@AMPAAIzMonaco



“The underlying theme of the medical project that I have the honour of coordinating as Clinical Director at the Princess Grace Hospital in Monaco is based on “providing care”. This applies in particular to people with Alzheimer’s disease and related disorders, who are often anxious and made vulnerable through a loss of bearings, but are nevertheless still sensitive to an empathic approach.

Why such strong involvement centred on this disease? Well, today we cannot ignore the medical, societal and ethical challenges represented by this disease’s consequences.

The mobilisation we initiated in the Mediterranean basin aims to offer support to the relevant stakeholders in each country who have been struggling in the past years. With the Mediterranean Alzheimer Alliance, we are striving to meet the needs of this region, acting as a catalyst for energy and knowledge. The network’s main priorities are to enable exchanges and experience pooling, fostering partnerships, whether academic, scientific or charity-based, promoting training programs for professionals and supporting on-the-ground initiatives.

Concerning Alzheimer’s disease and related disorders, it must be concluded that the needs of these countries are numerous and the range of responses are varied. This report sheds light on the priorities to be implemented and the range of issues these countries are facing. It also reminds us that developing support measures for patients and their carers requires real structural reforms, which should be anticipated as of now.

I am particularly happy that AMPA is pioneering this show of solidarity towards our Mediterranean neighbours”.

Professor Alain Pesce

Vice-President, AMPA, Head of the geriatric services in Monaco,
Princess Grace Hospital (Monaco)

ABOUT ALZHEIMER’S DISEASE AND RELATED DISORDERS

Alzheimer’s disease was first described by the German neuropsychiatrist, Aloïs Alzheimer in 1906 as a “chronic disease of the cerebral cortex”. The illness has borne his name ever since.

On a clinical level, Alzheimer’s disease is a progressive pathology, which manifests itself by memory disorders and a gradual decline of cognitive functions, mainly associated with behaviour and/or psychological disorders, evolving towards loss of autonomy.

Alzheimer’s disease is classified as a form of dementia. According to the World Health Organisation, dementia is a “syndrome – usually of a chronic or progressive nature, in which there is deterioration in cognitive function (the ability to process thought), beyond what might be expected from normal ageing. It affects memory, thinking, orientation, comprehension, calculation, learning capacity, language, and judgement. Consciousness is not affected. The impairment in cognitive function is commonly accompanied, and occasionally preceded, by deterioration in emotional control, social behaviour, or motivation”.

Alzheimer’s disease is the most common form of dementia, as it represents approximately 70% of all cases. However, there are other diseases which share some of the same symptoms as Alzheimer’s disease, with their own unique characteristics: these are called related disorders. The most common are known as Lewy Body Dementia, vascular dementia and Parkinson’s disease.

It is important to note that hereditary cases of Alzheimer’s disease with a genetic cause are very rare (1%). Anyone can develop the disease without having a family history.

There is still no cure for Alzheimer’s disease. However, some medical treatments can influence certain symptoms of the disease, such as behavioural disorders. Likewise, non-pharmacological therapies (called psychosocial interventions) can improve the well-being and quality of life of people with Alzheimer’s disease and related disorders and their carers.

ABOUT THE *MEDITERRANEAN ALZHEIMER ALLIANCE*

Upon the initiative of the Monegasque Association for research on Alzheimer's disease, the *Mediterranean Alzheimer Alliance* was launched in 2013 and currently has 17 member countries: Algeria, Cyprus, Croatia, Egypt, France, Greece, Italy, Lebanon, Libya, Malta, Morocco, Monaco, Portugal, Slovenia, Spain, Tunisia and Turkey.

THE OBJECTIVES

The *Mediterranean Alzheimer Alliance* is the only network composed of Alzheimer associations, scientific experts and healthcare professionals from each country.

The *Mediterranean Alzheimer Alliance's* main objectives are to:

- Support *Mediterranean Alzheimer's Alliance* members in the development of their initiatives
- Defend interests, needs and specificities of Mediterranean people with Alzheimer's disease and related disorders, and their family carers
- Ensure that Alzheimer's disease becomes a priority in this region
- Encourage and promote associative, scientific and academic collaborations in the Mediterranean region
- Share, exchange and disseminate knowledge and practices in the Mediterranean region
- Improve the well-being and quality of life of people with Alzheimer's disease and their families in the Mediterranean region

THE FIRST ACHIEVEMENTS

Organisation of Mediterranean scientific conferences

- 2013: *Scientific Congress on Alzheimer's Disease and the Mediterranean*, Marrakech
- 2014: *International Conference «Alzheimer and the Mediterranean: working together for a better understanding»*, Lisbon
- 2015: *1st Mediterranean Conference on Alzheimer's Disease and Related Disorders*, Thessaloniki

Support for local initiatives

- Opening of the first Alzheimer pilot centre in Essaouira (Morocco) in April 2015 (first information, assistance, support, respite and research platform for people with Alzheimer's disease and their families in southern Morocco)
- Alzheimer's disease was part of the Coeur de Gazelles medical caravan for the first time during the 25th edition of the Rally *Aïcha des Gazelles* (neurological consultations, information and awareness raising for families)

Mediterranean research

- Publication of the first "Alzheimer and the Mediterranean" report in 2016
- Development of research on emergent topics in the Mediterranean

Development of Mediterranean partnerships

- Academic, scientific and associative exchanges between the two shores
- Training for healthcare professionals

THE MEMBERS

Associations:

- Algeria: ASMGA Alzheimer Club
- Cyprus: Cyprus Alzheimer Association
- Croatia: Alzheimer Croatia
- Egypt: Egypt Alzheimer Society
- France: France Alzheimer 13
- Greece: Panhellenic Federation of Alzheimer's Disease and Related Disorders
- Italy: Alzheimer Uniti Italia
- Lebanon: Alzheimer Association Lebanon
- Libya: Libyan Society for Alzheimer patients
- Malta: Malta Dementia Society
- Morocco: Sud Maroc Alzheimer
- Monaco: AMPA
- Portugal: Alzheimer Portugal
- Slovenia: Alzheimer Slovenia
- Spain: Fundació ACE
- Tunisia: Alzheimer Tunisia
- Turkey: Turkish Alzheimer Association

Non-associative members:

Pr Myriem Abada Bendid (Algiers), Pr Sandrine Andrieu (Toulouse), Dr Nawal Adali (Marrakech), Pr Joël Ankri (Paris), Pr Luisa Bartorelli (Rome), Dr Mercè Boada Rovira (Barcelona), Pr Mathieu Ceccaldi (Marseille), Dr Anne Marie Duguet (Toulouse), Espace Ethique Méditerranéen (Marseille), Fondation Médéric Alzheimer (Paris), Pr Riadh Gouider (Tunis), Dr Stephane Guétin (Montpellier), Pr Olivier Guérin (Nice), Pr Najib Kissani (Marrakech), Karine Lefevre, Ecole des hautes Etudes en Santé Publique, Rennes, Dr Sandrine Louchart de la Chapelle (Monaco), Philippe Migliasso (Monaco), Pr Ninoslav Mimica (Zagreb), Dr Nabil Naja (Beirut), Pr Alain Pesce (Monaco), Pr Charles Scerri (Valletta), Pr Hala Sweed, Egyptian Society of Geriatrics and Gerontology (Cairo), Pr Jacques Touchon (Montpellier), Pr Magda Tsolaki (Thessaloniki), Pr Bruno Vellas (Toulouse)

International Organisations (observers):

- Alzheimer Europe
- Alzheimer's Disease International

THE SCIENTIFIC COMMITTEE

In 2015, the *Mediterranean Alzheimer Alliance* created a scientific committee, chaired by Professor Jacques Touchon (Montpellier, France). This committee brings together the principal Mediterranean area researchers in biomedical and clinical research and human and social sciences. Its objective is to promote and develop research in this region.

ABOUT THE REPORT

OBJECTIVES

This report is the first paper to discuss the issues concerning Alzheimer's disease and related disorders in the Mediterranean region. It aims to assess needs related to the illness and to analyse the emerging medical and social challenges in the region. The report also makes recommendations on a regional and international level in order to be able to anticipate solutions and provide better support and care for people with Alzheimer's disease and related disorders.

METHOD

This report presents the results of the ALZMED (Alzheimer and the Mediterranean) study, which was carried out by the Monegasque Association for research on Alzheimer's disease between June 2013 and July 2014. This study was composed of:

- A review of national and international literature on issues related to Alzheimer's disease in the Mediterranean region
- A survey in the form of a declarative questionnaire, conducted in member countries of the *Mediterranean Alzheimer Alliance*: Algeria, Croatia, Cyprus, Egypt, Spain, France, Greece, Italy, Lebanon, Libya, Malta, Morocco, Monaco, Portugal, Slovenia, Tunisia and Turkey, via their respective national Alzheimer associations

The survey, composed of 78 questions, addressed 11 themes:

1. Prevalence, 2. Public health priorities, 3. Legal and ethical issues, 4. Socio-economic cost, 5. Diagnosis, 6. Care and support, 7. Healthcare professionals, 8. Medical treatments and psychosocial interventions, 9. Research and prevention, 10. Family carers, 11. Public perceptions.

Each theme of the report was analysed through 3 different angles: an overview, a summary of the challenges and perspectives, and developing recommendations.

The report also includes several interviews with Mediterranean and international experts, supporting the results of the ALZMED survey and highlighting innovative initiatives in the Mediterranean area.

This report was drafted during three workshops, which brought together the members of the *Mediterranean Alzheimer Alliance* in Malta, Thessaloniki and Ljubljana. It has also had been proofread by Fabrice Gzil (Doctor of Philosophy, Head of the Study and Research Centre of the M d ric Alzheimer Foundation, France) and Sandrine Andrieu (Professor of epidemiology and public health at the University of Toulouse, Director of the INSERM–University of Toulouse Research Unit UMR1027 and Director of the French Society of Geriatrics and Gerontology, France).



« Mediterranean rim countries are united by historical, geographical and cultural links, but more importantly by common values of solidarity.

In many Mediterranean countries, there is still little knowledge about the problems surrounding Alzheimer's disease, which remains under-estimated and insufficiently documented. This situation is set to have a drastic impact on health and society in years to come.

The objective of this report is to gain an initial understanding of these countries' needs, to understand the measures already in place and to identify innovative initiatives in the Mediterranean region. This report will also highlight the issues and challenges for both the medical and social sectors and identify paths for reflection and action. The Mediterranean Alzheimer Alliance will also use this report to make recommendations and call for those concerned to anticipate the impact that Alzheimer's disease and related disorders will have on the Mediterranean region in the future.

I would like to thank all the members of the Mediterranean Alzheimer Alliance for their trust and commitment. By working together, we can foster and organise suitable solutions, adapted to the specificities of this region.

I also call for other countries and stakeholders of the Mediterranean region to join us in this unprecedented mobilisation».

Federico Palermi

Executive Director, AMPA, *Mediterranean Alzheimer Alliance* Coordinator

«The original nature and the challenge of the Mediterranean Alzheimer Alliance is to encourage collaboration between scientists, Alzheimer associations and professionals from each Mediterranean country. The pooling of different approaches and expertise makes this network extremely rich. In order to organize our thinking, the Mediterranean Alzheimer Alliance set up a scientific committee. This committee will identify innovative research topics in the Mediterranean area and develop new scientific and academic collaborations between the two shores. I am convinced that the distinctive features of the Mediterranean region make it particularly interesting for new research on Alzheimer's disease».



Jacques Touchon,

Professor Emeritus, Montpellier School of Medicine,
President of the Mediterranean Alzheimer Alliance scientific committee (France)



PREVALENCE

1

AN ALARMING RISE IN THE NUMBER OF PEOPLE WITH ALZHEIMER'S DISEASE AND RELATED DISORDERS

According to latest available data from *Alzheimer's Disease International (World Alzheimer Report 2015: the global impact of dementia: an analysis of prevalence, incidence, costs and trends)*, the number of people with Alzheimer's disease and related disorders is set to increase significantly. In 2015, 46.8 million people were thought to have Alzheimer's disease and related disorders around the world. This number is set to double every twenty years to reach 131.5 million people in 2050. In their report, Professors Martin Prince and Anders Wimo also demonstrated that this rise will be even more significant in low and middle-income countries. The Mediterranean region has not escaped this phenomenon. In Italy for example, the number of people with Alzheimer's disease and related disorders is set to increase by 83.08% by 2050. In Lebanon, this increase may be 310%.

2

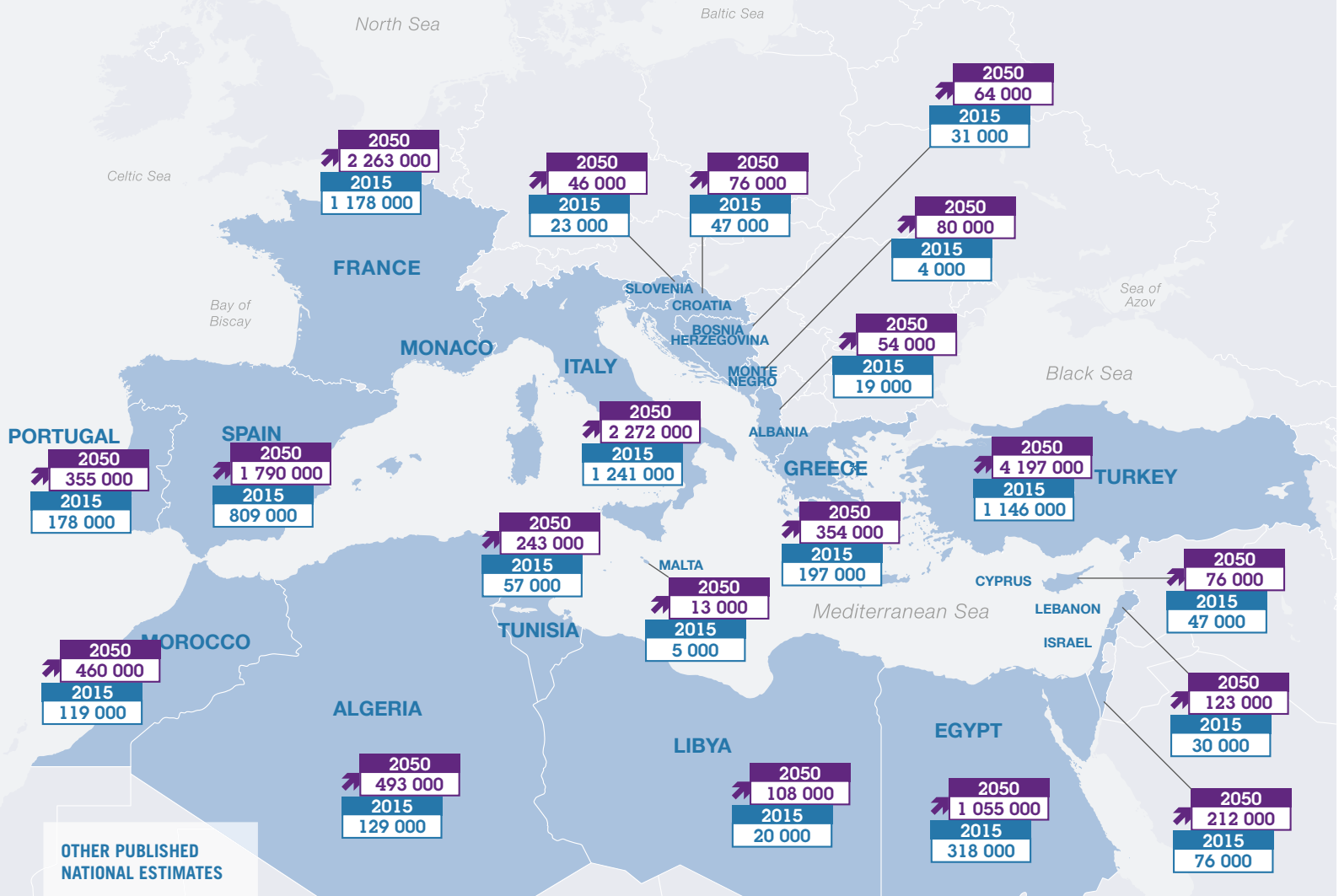
A LACK OF EPIDEMIOLOGICAL STUDIES IN THE MEDITERRANEAN AREA

Few Mediterranean countries are able to provide accurate epidemiological data regarding Alzheimer's disease and related disorders. Northern Mediterranean countries either have official estimates provided by their own governments or use the national or European prevalence studies (for instance, *Alzheimer Europe*, EUROCODE 2008).

Conversely, southern Mediterranean countries rarely have their own national data and rely on regional or international estimates (*Alzheimer's Disease International*, World Health Organisation). However, it may be noted that Egypt has a national prevalence study whose methodology was recognised by the World Health Organisation and acting as reference for the prevalence studies developed by country of the Middle East and North Africa region.

Apart from *Alzheimer's Disease International* estimates (see map hereafter), a few countries have conducted their own prevalence studies. Only the published scientific studies were taken into account here and complement *Alzheimer's Disease International* data (see table opposite).

ESTIMATED NUMBER OF PEOPLE WITH ALZHEIMER'S DISEASE AND RELATED DISORDERS IN 2015 AND 2050 (Estimations provided by Alzheimer's Disease International, 2015)



OTHER PUBLISHED NATIONAL ESTIMATES

COUNTRY	YEAR	NUMBER OF PEOPLE WITH ALZHEIMER'S DISEASE AND RELATED DISORDERS	REFERENCE
Malta	2012	6,071	Anthony Scerri, Charles Scerri. Dementia in Malta: new prevalence estimates and projected trends. Malta Medical Journal Volume 24 Issue 03 2012.
Italy	2015	1,000,000	Teresa Di Fiandra, Marco Canavelli, Alessandra Di Pucchio, Nicola Vanacore and the Italian Dementia National Plan Working Group. The Italian Dementia National Plan, Ann Ist Super Sanità 2015, Vol. 51, No 4 : 261-264.
Greece	2014	150,000	Magda Tsolaki, Constantinos Fountoulakis, Ilias Pavlopoulos, Eleni Chatzi and A. Kazis. Prevalence and incidence of Alzheimers disease and other dementing disorders in Pylea, Greece, AM J Alzheimers dis other demen 1999 14: 138
Slovenia	2015	31,000	Official data from the national Association (Alzheimer Slovenia)
France	2014	850,000	Neuro-degenerative diseases plan 2014-2019
Monaco	2015	400	Princess Grace Hospital, Estimation based on an extrapolation of French prevalence figures
Croatia	2015	86,000	Official data from the national Association (Alzheimer Croatia)



QUESTION TO SANDRINE ANDRIEU

Professor of epidemiology and public health at the University of Toulouse, Director of the INSERM–University of Toulouse Research Unit UMR1027 and the Ageing and Alzheimer Disease research team and Director of the French Society of Geriatrics and Gerontology (France)

As an epidemiologist, can you tell us why it is important to carry out national prevalence and incidence studies on Alzheimer's disease and related disorders?

It is essential to carry out cohort studies in order to identify risk factors for Alzheimer's disease. Only knowledge of these factors, and in particular the modifiable risk factors, can help us to define prevention strategies which, if proven to be efficient, may lead to a reduction in the number of cases of the disease. Indeed, delaying the start of the disease by just a few months would be enough to considerably reduce the number of cases and to have an impact on public health.

Furthermore, cohort studies allow us to become aware of the disease's prevalence, namely its frequency and incidence, or the number of new cases which occur in a given period.

This data is vital for planning health and welfare policies. For some diseases, we can use indirect indicator analysis, (e.g.: consumption data for a given drug) allowing us to estimate with a certain amount of confidence, the number of cases of the disease studied. For Alzheimer's disease, this type of data does not enable us to estimate the number of cases with enough precision and cohort studies are therefore essential.

Can you explain how a cohort study is carried out, practically speaking?

The constitution of a cohort involves obtaining information from several thousand elderly subjects (between 3,000 and 5,000 approximately) and ensuring that they are free of the disease at the start, organising a data collection which is identical for each subject, with a planned frequency (10 to 30 years) to obtain a sufficient number of cases (several hundred) to analyse the risk factors.

This data must then be entered, verified and analysed. This requires significant logistics and only a dedicated team can reach their objectives.

It would be very interesting to set up this kind of study with an identical methodology and tools in different Mediterranean countries to study the frequency of the disease.

Why is it important to carry out new prevalence and incidence studies on Alzheimer's disease and related disorders and not simply rely on existing ones?

First, because the criteria for defining the disease change with time as our knowledge of it develops. But also because we must take into consideration the changes between one generation and the next, within a given country or territory. We know that the events we go through during our lives can have an influence on our risk of developing the disease.

In France, epidemiological work carried out in the 1980s and 90s, demonstrated, for example, that elderly people who had obtained their school-leaving certificate, had a lower risk of developing Alzheimer's disease than those who had not obtained it, once they reached old age. What is the present situation? Several decades have gone by since this data was collected, what does it mean for the new generations to have obtained a school leaving certificate? At the time, this meant that the person could aspire to a given career.

We must also take into account sociocultural differences in the various countries and territories. Beyond the obvious and measurable difference such as they can be observed in terms of exposure to socio-economic factors (level of education, revenue, professional life) and environmental factors (pollution and pesticides), subtler differences, which are hard to quantify, should also be addressed (care from family members, cohabitation customs, tolerance regarding cognitive impairment or behavioural disorders and social norms).

In terms of the prevalence and incidence of Alzheimer's disease, the most recent analyses and data show that these figures tend to decline over time.

“46,8 million people worldwide are living with dementia in 2015.

This number will almost double every 20 years, reaching 74.7 million in 2030 and 131.5 million in 2050.

Around the world, there will be 9,9 million new cases of dementia in 2015, one every three seconds”

Alzheimer's Disease International, 2015

“The burden of Alzheimer's disease and other dementias, which is projected to surge in the coming decades, poses a serious threat to the sustainable development of economies and the social welfare systems of Europe”

The Lancet Neurology Commission, 2016

CHALLENGES AND PERSPECTIVES

Due to ageing, we know that Mediterranean rim countries will be faced with a considerable increase in the number of people with Alzheimer's disease and related disorders.

According to recent international studies, this increase will be even more significant in low or middle-income countries mainly due to the growing life expectancy of the population.

To date, the southern Mediterranean countries lack national epidemiological data concerning the prevalence (frequency) and incidence (the number of new cases) of Alzheimer's disease and related disorders.

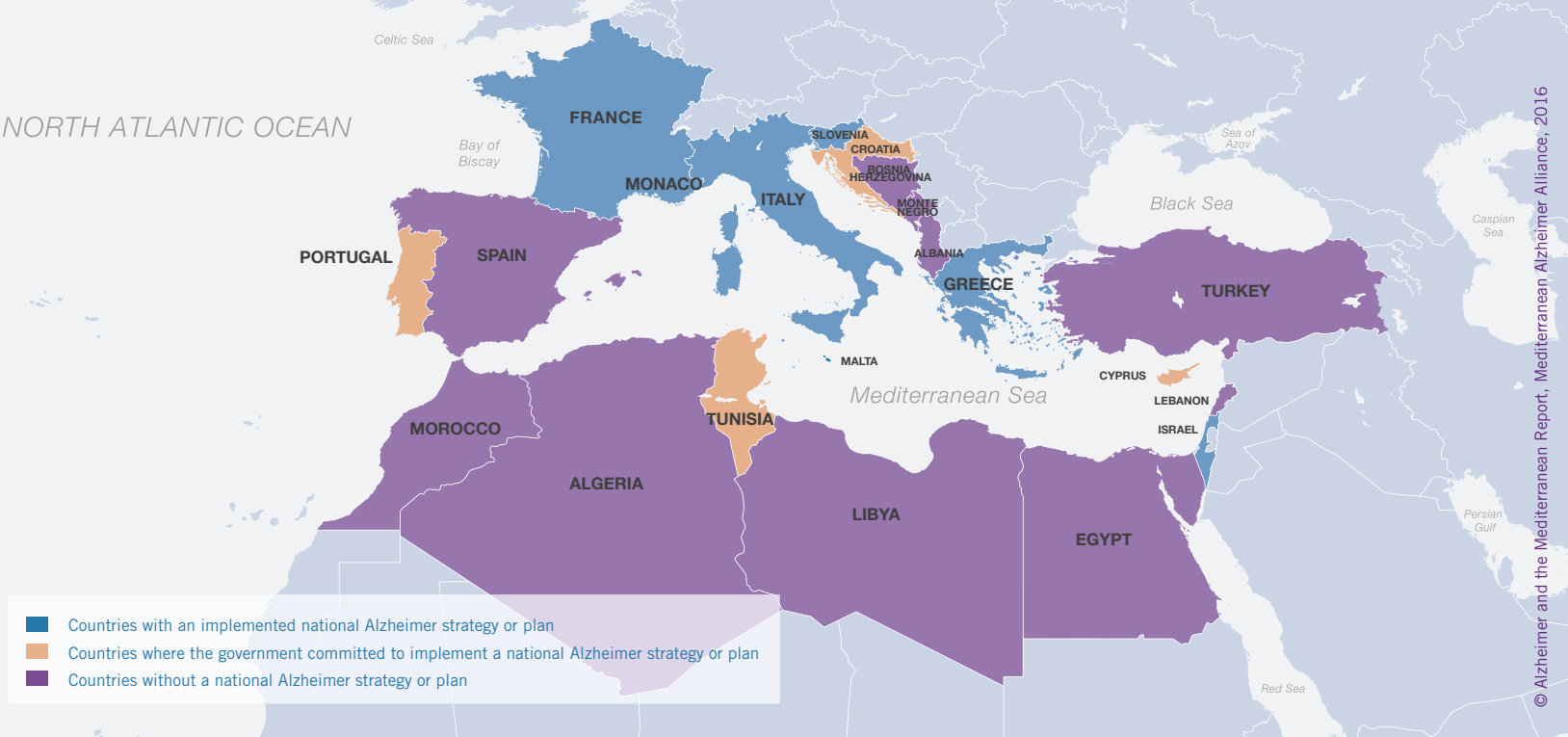
It is therefore difficult to evaluate the magnitude of the phenomenon and thus to anticipate it.

RECOMMENDATIONS

The *Mediterranean Alzheimer Alliance* calls on each Mediterranean country:

- **To take into consideration the alarming rise in the number of people with Alzheimer's disease and related disorders**
- **To develop national prevalence and incidence studies, specific to Alzheimer's disease and related disorders, according to international standards in force**
- **To anticipate the individual and collective responses to be sought**

NORTH ATLANTIC OCEAN



© Alzheimer and the Mediterranean Report, Mediterranean Alzheimer Alliance, 2016

PUBLIC HEALTH PRIORITIES

1

PUBLIC POLICIES WHICH DO NOT RECOGNISE ALZHEIMER'S DISEASE AS A PRIORITY

Many Mediterranean countries do not currently recognise Alzheimer's disease and related disorders as public health priorities. In these countries, no national Alzheimer strategy or plan is implemented. This is the case in ten Mediterranean countries: Albania, Algeria, Bosnia and Herzegovina, Egypt, Lebanon, Libya, Morocco, Montenegro, Spain and Turkey.

However, certain countries do have public health policies regarding the elderly, loss of autonomy or mental health; which may concern people with Alzheimer's disease and related disorders. For instance, in Spain, Catalonia has had a public health plan since 1998, not specific to Alzheimer's disease and related disorders (although these are alluded to in various subjects such as diagnosis and treatment). In Lebanon, while there is no national Alzheimer strategy or plan, a handful of government actions benefitting the elderly are implemented.

2

EMERGING ALZHEIMER'S PLANS

In other countries, discussions on implementing a national Alzheimer strategy or plan have been initiated by the associations, in partnership with the public authorities. However, these initiatives have yet failed to achieve concrete results.

In Cyprus in 2008, the national association campaigned for a national Alzheimer strategy or plan to be drawn up and implemented. The former Minister of Health had entrusted the project to a multidisciplinary committee in the Ministry. In 2013, the strategic plan was approved and its budgeting is presently being studied. In Portugal, the national association has been working on drawing up and implementing an Alzheimer's plan since 2006. At the conference organised by Alzheimer Portugal in October 2009, a document entitled, "Alzheimer's National Intervention Plan" was drawn up and delivered to the political parties. In October 2010, parliament approved two resolutions proposing that Alzheimer's disease

and related disorders be recognised as a national priority and calling for the creation of a national Alzheimer's plan or programme. Finally, in December 2014, a working group, organised by the General Health Directorate was set up in order to create the first Alzheimer's plan.

In Croatia, an alliance of relevant stakeholders was founded in 2014 with the aim of challenging the public authorities regarding the need to implement a national Alzheimer strategy or plan. Lastly, in Tunisia, discussions on implementing a national Alzheimer plan have been initiated in partnership with all the relevant ministries, the scientific societies and the association Alzheimer Tunisia. This plan, which addresses topics such as epidemiology, care pathways, training, research, legal and ethical issues, family carers support among others, will be submitted to the Parliament for approval in September.

3

ONLY SEVEN MEDITERRANEAN COUNTRIES WITH AN ALZHEIMER'S PLAN

In Italy, an Alzheimer's plan was signed by the Ministry of Health in October 2014 and presented in Rome on November 14, 2014. The Plan had several aims: to set up social and health measures and initiatives, to create a dementia network and implement it throughout the country, to offer an adequate response in terms of care and support, and to increase awareness to reduce stigmatisation and improve quality of life for people with Alzheimer's disease and their families. Other initiatives include promoting research into Alzheimer's disease and related disorders as public health priorities, training professional teams and carers, and social inclusion for patients.

In December 2014, Greece's parliament adopted a law ensuring a national dementia strategy would be created. This law provided for a dementia and Alzheimer's disease Observatory, which is an independent institution responsible setting up and coordinating the new plan.

On April 2, 2015, Malta launched a national 9-year Alzheimer's strategy, (see box page 14).

In 2001, France was the first country in Europe to launch an Alzheimer's plan. The first Plan (2001-2005) aimed to respond to the growing number of people with Alzheimer's disease. The second Alzheimer plan (2004-2007) included various improvements, such as adding Alzheimer's disease to the list of long-term illnesses, resulting in patients

receiving 100% reimbursement for medical care. It also led to many institutions and day care centres being established. In 2008, the President of the French Republic, Nicolas Sarkozy, launched the third Alzheimer's plan (2008-2012), backed by ambitious funding in the amount of 1.6 billion Euros. Its significant developments included unprecedented funding for research, the improvement of care in institutions for patients, and additional support for their carers. On November 18, 2014, under François Hollande's presidency, the Minister of Health announced a "neuro-degenerative diseases" plan.

In Monaco, the global gerontological strategy is inspired by the third French plan.

In Israel, a group of interdisciplinary experts has drawn up recommendations concerning Alzheimer's disease and related disorders. Their work has been presented to the Ministry of Health. A national Alzheimer plan was adopted in 2013 and a follow-up committee was also set up.

Lastly, in Slovenia, the Ministry of Health approved the first Alzheimer national strategy on May 25, 2016. The strategy addresses different topics regarding the care of people with Alzheimer's disease and related disorders such as early diagnosis, access to treatments and research, access to social services, palliative care, raising awareness etc.



QUESTION TO JEAN GEORGES

Executive Director, Alzheimer Europe
(Luxembourg)

Most northern European countries now have an Alzheimer's Plan, how can you explain that this is not yet the case in some southern European states?

It is true that northern European countries have set an example by developing Alzheimer's plans or strategies to combat dementia. This is currently the case in Belgium, Denmark, Finland, Ireland, Luxembourg, Norway, the Netherlands, the UK, (with regional plans for England, Scotland, Northern Ireland and Wales) and Sweden.

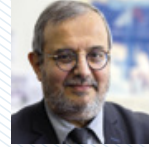
Nevertheless, we must not forget that one Mediterranean country was the model and precursor for this movement. France was in fact the first country to develop such a plan and was the driving force behind greater European collaboration on issues concerning dementia.

Greece and Italy were the last countries to adopt plans in 2014 and Malta, Spain and Slovenia are currently developing their strategies. Both Portugal and Cyprus started to develop their plans, but the effects of the economic and financial crisis have hampered these developments. Southern European countries are therefore following the example of northern countries and it is mainly in eastern European countries where dementia does not seem to be considered as a public health priority.

Alzheimer Europe is currently calling for a Europe-wide Alzheimer Plan. Could you stipulate the objectives of this initiative?

Alzheimer Europe and our national associations adopted the *Glasgow Declaration* during our annual conference in 2014. In this Declaration, we call for the development of a European plan. Through such a plan, we hope to consolidate research efforts for Alzheimer's disease, increase funding for research and promote exchange of best practices in terms of treatment and care between European countries.

Finally, we call for the appointment of an official in charge of dementia at the European Commission, to coordinate the various European initiatives. We have also urged the European public to support this initiative.



QUESTION TO JOËL ANKRI

Professor of Public Health, Vice-President of the
Monitoring Committee for the Neurodegenerative
Disease Plan's (2014-2019) (France)

You evaluated the third French Alzheimer's Plan. What did you learn from this plan?

Since 2000, France has had three successive Alzheimer's plans and a fourth plan, also covering neurodegenerative diseases, began at the end of 2014. When evaluating the 2008-2012 plan, we highlighted several points and three in particular. The first is that in terms of medical and social care in treating Alzheimer's patients and their carers, we must always adopt the bottom-up approach, as opposed to the top-down approach, so that the proposed new organisations can reach out to their public in the relevant area without being burdened by specifications which are incompatible with on-the-ground realities. The second is that we must continue to strive for social inclusion of people with Alzheimer's disease and their carers and integrate public health and medical-social welfare to end the fragmentation of the French system, which is the cause of care dysfunctions. Finally, support for research must also be pursued, with an integrative vision of fundamental research including human and social science research.

What recommendations would you make to Mediterranean countries when implementing their future Alzheimer plans?

It is hard to make recommendations to countries which do not have the same history, culture and especially health and social protection systems. Innovation cannot really be exported from one country to another. Of course, we must pay particular attention to the treatment of behavioural disorders, the needs of carers and ensure support is offered as the disease evolves, providing alternative housing where required. The shift of professional practices towards recognised best practice standards is also a key issue, as well as improving the evaluation process for cognitive functions, diagnosis of the disease and accessibility to all of these resources. Lastly, at advanced stages of the disease, we all aim to ensure quality of life, wherever the person lives, and to enable high quality end-of-life care which respects the desires, dignity and comfort of the patient.

MALTA, A PARTICIPATIVE STRATEGY

Given that 28% of the Maltese population will be elderly in 2050, 1.5% of whom will have Alzheimer's disease and related disorders, the Parliamentary Secretary for the Elderly and Community Care, in 2009, launched the Maltese Strategic Group for Dementia. This working group developed innovative and participative initiatives, actively involving the public in their endeavours. A website was created where Maltese people could communicate their needs regarding this disease. Despite the financial crisis, which initially delayed the set-up of a nationwide strategy, a hotline was created, offering information to improve awareness, and drugs are now provided free of charge. In January 2014, the first draft of the national dementia strategy was published and

issued for public consultation the following month. This project focuses on various intervention points, such as awareness raising and developing understanding of the disease, diagnosis, professional training, treatment, research and ethics surrounding Alzheimer's disease and related disorders. This 9-year strategy was launched on April 2, 2015 establishing Malta as the 5th Mediterranean country to have a national Alzheimer plan or strategy. A version of this plan especially designed for people with Alzheimer's disease and related disorders was also published.

<https://activeageing.gov.mt>



QUESTION TO LUISA BARTORELLI

Geriatrician, Professor of Geriatric psychiatry,
President of Alzheimer Uniti (Italy)

Italy has recently benefited from an Alzheimer's plan in the Mediterranean area. Are you satisfied with the objectives and resources offered in the framework of this Plan?

At the end of the second European Semester chaired by Italy in 2014, the National Dementia Plan (PND) for Alzheimer's disease and related disorders was finally published. However, unlike the French plan, no additional funding has been earmarked for this plan and the twenty Italian regions will have to use their initial resources. Nonetheless, we consider this plan a success. An achievement for which the Italian associations worked extremely hard.

What do you consider to be the key points of this Alzheimer plan?

We now have guidelines from the government that are specific to Alzheimer's disease and related disorders. A person-centered quality care network, focusing on individuals with Alzheimer's disease, their family and GP is established with the various health and social services, to meet the needs of people with Alzheimer's disease in the different stages of the disease.

Home care is promoted and special attention is given to assistive home-based services. The role of the hospital is therefore restricted to people presenting medical or surgical emergencies and for as short a time as possible. Retirement homes must have specialised units for people with Alzheimer's disease and related disorders. Diagnosis should be carried in the early stages of the disease at day care centres or at expert centres within the territory.

Day care centres and other support services in Italy are trained in best practices. The associations also have an important role in meeting the needs of people with Alzheimer's disease and their families.

The plan also includes recommendations on the need to safeguard the dignity of people with Alzheimer's disease and related disorders, by mitigating the negative image surrounding the disease, and on the continuity of care. Lastly, it advocates setting up a computerized system to enable the regions and the State to converge on the implementation of the Plan. We hope that this will all soon be implemented.

"It is vital to plan, invest and cooperate in this field today, both to contain the social costs of these diseases, as well as to offer hope, dignity and healthier lives to the millions of sufferers and their families"

European Commission, 2009

CHALLENGES AND PERSPECTIVES

By acknowledging that Alzheimer's disease and related disorders are public health priorities in a national Alzheimer strategy or plan, Mediterranean countries will be in a better position to meet the specific needs of people with Alzheimer's disease and their carers.

This will also give them the opportunity to mobilise the various relevant stakeholders, to design and develop new methods of care in their country and earmark the funding needed to reform social protection systems.

RECOMMENDATIONS

The *Mediterranean Alzheimer Alliance* calls on each Mediterranean country:

- To recognise Alzheimer's disease and related disorders as a public health priority
- To develop a comprehensive national Alzheimer strategy or plan adapted to the needs of people with Alzheimer's disease and their families, with specific and long-term funding
- To monitor, coordinate and evaluate this national Alzheimer strategy or plan including all of the relevant stakeholders and the voluntary sector in particular



LEGAL AND ETHICAL ISSUES

1

THE FUNDAMENTAL RIGHTS OF PATIENTS RECOGNISED BY EACH LEGAL SYSTEM

Certain rights are recognised for patients in all the Mediterranean countries. Some of these rights, such as the right to health, are guaranteed either by the Constitution, or by legislative or regulatory texts. Some of these rights are general and universal in scope (respect for dignity, integrity, privacy, intimacy and safety). Others refer more specifically to treatment provided by an establishment or service (admission procedure, consent to care and access to information). Most of these texts are based on international and European agreements and for southern European countries, often constitute a national transposition of community directives. We note that despite the existence of recognised rights for patients in all Mediterranean legal systems, the concrete application of these texts and their implementation can raise ethical and legal issues, specifically in the case of people with Alzheimer's disease and related disorders. This fact has not been analysed in this report and is worthy of further investigation.

In Egypt for instance, the Constitution sets down the obligation for the government to guarantee the rights of the elderly, particularly as regards health, culture, social issues and pensions.

The Portuguese Constitution also guarantees the right to health, based on the principles of respect for dignity, privacy, the right to information, non-discrimination and physical and moral integrity. The Portuguese Penal Code qualifies as illicit any clinical intervention carried out without the patient's prior, informed consent.

In Malta, the Mental Health Act and the Charter for Patient rights and responsibilities protect the people with mental health disorders, including those with cognitive impairment and behavioural disorders and cover rights such as the right to information, dignity and privacy. In addition, the Office of the Commissioner for Mental Health promotes and safeguards the rights and interests of persons with mental disorders and their carers, such that they can benefit from a better quality of life through the maximization of their potential.

In Spain, concerning for example the handling of personal data, the Organic Law on the Protection of Personal Data, and the Spanish Biomedicine Law guarantee the rights of Spanish patients.

In Cyprus, too, many rights are protected by the 2004 Law for the safeguard and protection of patients' rights, such as the right to health care and treatment, respect for dignity, access to health care, consent, information, the contribution of patients to scientific research, privacy, representation and non-discrimination. The 1997 Mental Health Law (amended in 2003 and 2007) protects the right of patients in the framework of admission procedures and guarantees their right to refuse to be examined.

In Slovenia, the 2008 Patients' Rights Act safeguards the rights of patients and specifies procedures should these rights be flouted.

In Croatia, patients are protected by the 1993 Health Care Act and the 1997 Act for the protection of people with mental disorders. In 2004, the Act on the protection of patients' rights was also adopted in conformity with European law.

In Tunisia, patient protection is guaranteed by law of 31 October 1994. This is based upon several fundamental principles, such as preserving health and dignity and combatting all forms of discrimination and exclusion.

In Turkey, the laws of May 15, 1987 and October 11, 2011 define the organisation of healthcare and the responsibilities of the Ministry of Health. In addition, the law of August 1, 1998 describes patients' rights.

In France, people are protected by the law of January 2, 2002 reforming social and medical-social systems and the law of March 4, 2002 regarding patients' rights and the quality of the health care system; as well as the law of April 22, 2005 concerning patients' rights and end-of-life. The Social Action and Families Code recalls for example that *"exercising individual rights and freedoms is guaranteed to all individuals cared for in health care establishments or by social and medical-social services"*. In January 2016, the law on the adaptation of society to an ageing population came into force. It reasserts the rights and liberties of elderly people and aims to improve their quality of life as well as the everyday life of their carers.



2

LEGAL PROTECTION SYSTEM FOR ADULTS VARY SIGNIFICANTLY

Depending on his or her family, economic and social context, it may become necessary to protect a vulnerable individual and their interests. In that case, that individual's exercising of their rights may be monitored or limited by a court in order to protect the person from any abuse.

Three protection systems exist in most Mediterranean countries including France, Morocco, Italy and Spain: judicial protection, temporary guardianship and guardianship. It should be noted that some countries, such as Monaco, do not enjoy a judicial protection system. All individuals affected by a decline in mental faculties may benefit from this system. Likewise, in most cases, incapacity to protect one's interests must be medically certified. Furthermore, the legal protection measure is, in most cases, entrusted to a family member.

However, their legal scope and their implementation of these systems have not been analysed in depth in this report.

3

POORLY DEVELOPED LEGAL MEASURES FOR ANTICIPATING NEEDS

Some national laws have brought in legal framework allowing adults still capable of doing so, to nominate a person to express their desires or to draw up a list of their wishes in anticipation of the day that they are no longer able to express themselves. Whether it be a health care proxy, advance directives or a power of attorney, the advantage of these measures is that adults can plan for their future in advance, without recourse to any legal proceedings. The legal scope of these measures, their legal form and their field of application vary according to the legal system in question.

These anticipation measures only exist in a few Mediterranean countries; namely France, Slovenia, Portugal, Spain and Malta. France, for example, boasts three measures. In Malta, only the power of attorney exists. In Italy, these measures are currently being debated by Parliament. In Cyprus, these issues were discussed in Parliament several years ago without translation into law.

4

ABUSE AND “GOOD TREATMENT”: MEASURES TO BE PROMOTED

Few Mediterranean countries have measures regarding the fight against abuse and the promotion of “good treatment” for dependent, elderly people. This is the case in particular in Greece, Lebanon, Egypt and Cyprus. This does not mean that abuse of vulnerable individuals is not reprehensible or punished by national legislation, but rather that the concepts of “good treatment” and abuse as recognised by the Council of Europe, are not currently being translated into law or into professional practices in most Mediterranean countries (see box hereafter).

5

STRUCTURING A SPECIFIC ETHICAL REFLECTION

Alzheimer’s disease and related disorders have complex consequences, (gradual loss of the ability to communicate and interact with one’s environment, etc.), which can make a person particularly vulnerable.

Hence, Alzheimer’s disease requires us to consider and structure a specific, ethical way of thinking, allowing stakeholders to share, discuss and take stock of common problematic situations, to analyse everyone’s practices in order to make decisions which are tailored to the health status of people with Alzheimer’s disease and related disorders and their families.

Based on the creation of the National Centre for Ethical Reflection and Neuro-Degenerative Diseases, as part of the French Alzheimer Plan, headed by Pr. Emmanuel Hirsch, an interdisciplinary centre for discussion, sharing and teaching knowledge and expertise should be encouraged in each Mediterranean country.



QUESTION TO EMMANUEL HIRSCH

University Professor, Director of the National Ethical Reflection Centre on Neuro-degenerative Disease (France)

In light of the urgency to dispense practice and care, what role can an “Ethical Reflection Centre on Alzheimer’s disease” actually achieve?

In view of the extreme consequences of this disease, when individuals are no longer able to express human emotions, how can practice and ethics be distinguished? Ultimately, only the ethical approach provides a link to life, solves puzzles, and thus helps us to rediscover a link with existence. We have a field-based approach, centred on the daily practices of all those who receive and provide care. We support the men and women who, despite the despair and frustration, steadfastly refuse to surrender in the face of this disease and who strive to ensure that patients retain their dignity and legitimacy.

As for ethics, a notion which can appear frightening -let’s be frank- for me it has a strong political dimension. When dealing with the disease, ethics definitely must be taken into consideration to protect the dignity and respect of patients and their loved ones. But there is also a collective obligation to address society’s duties towards all of its members and to address these in terms of law, and not in terms of morals. The Ethical Reflection Centre lies at the heart of all of the questions currently raised by Alzheimer’s disease and end-of-life.

Society cannot shy away from these questions which are numerous and multifaceted, practical, philosophical, psychological and legal in nature. Particularly because dependence is going to be one of the major social issues in the years to come. One of tomorrow’s key challenges is to factor in the vulnerabilities and interdependencies they generate. It is up to us to tackle them and to adapt our social covenant to involve every citizen in our community. At this time where we are looking at rebuilding our Republic, our commitment to support people with Alzheimer’s disease and their families is clearly a political emergency.



ABOUT THE CONCEPT OF ABUSE

In 1987, the Council of Europe defined abuse as violence characterised by “any act or omission committed by a person which may harm the life, physical or mental integrity or the freedom of another individual, or which severely affects the development of his/her personality and/or damages his/her financial security”.



QUESTION TO MARIA DO ROSARIO ZINCKE

Member of the audit committee,
Alzheimer Portugal (Portugal)

Has the Portuguese Parliament approved the implementation of the advance directives?

In 2012, the Portuguese Parliament passed a law regarding advance directives, which could take the form of a living will or involve the appointment of a health care proxy. Since this time, people have been able to provide advance directives and those regarding health issues, in order to anticipate a future situation of incapacity, such as, for example, the issue of refusing food or artificial hydration, in the case of a prolonged natural end-of-life process, the refusal of life support, the refusal to take part in experimental treatments or clinical trials and the refusal to receive palliative care.

This law allows citizens to draw up a document stating the type of treatment they would accept or refuse in a situation of future incapacity. The advance directives must respect the law and best practice. They may take the form of a living will or involve the appointment of a health care proxy.

Portuguese Law describes a living will as a written document that can be freely revoked at any time by the author - a capable adult – who expresses, in advance, his/her free and informed desire, with regards health care in a possible future situation of incapacity.

The health care proxy is described as a written document through which, the person appoints, in an explicit and free manner, a person to represent him/her in terms of health care in the case of future incapacity.

Can these advance directives be registered at a national level?

In 2014, the Health Ministry created the Living Will National Registration and the Living Will Form. This registration is completely free of charge and people can either fill in the official template or draw up their advance directives in a different format. Advance directives may be revoked at any time and have to be renewed every five years while the person remains “capable”, in the legal sense.

In 1992 it went on to classify the various types of abuse:

- Physical violence
- Mental or moral violence
- Medical or medicinal violence
- Active neglect
- Passive neglect
- Deprivation or violation of rights
- Material or financial violence

CHALLENGES AND PERSPECTIVES

People with Alzheimer's disease and related disorders are particularly vulnerable. The law must protect them throughout the duration of their illness and guarantee the enforcement of their rights for as long as possible.

Failure to impose adequate legal safeguards increases the likelihood that people with Alzheimer's disease and related disorders or their interests will be abused.

Moreover, the complexity of Alzheimer's disease and its implications requires an ethical reflection about the care and support to provide throughout the disease.

RECOMMENDATIONS

The *Mediterranean Alzheimer Alliance* calls on each Mediterranean country:

- To bring in legal protection mechanisms, which are proportionate to the vulnerability of people with Alzheimer's disease and related disorders
- To develop legal measures for anticipating needs and protecting the wishes of individuals who are unable to express themselves
- To promote initiatives to prevent abuse and promote positive treatment of people with Alzheimer's disease and related disorders
- To encourage and develop ethical reflection concerning care for people with Alzheimer's disease and related disorders and their families

OVERVIEW

1

FEW STUDIES CONCERNING THE SOCIO-ECONOMIC COST OF ALZHEIMER'S DISEASE IN THE MEDITERRANEAN AREA

On an international level, studies exist regarding the socio-economic impact of Alzheimer's disease around the world. For example, Alzheimer's disease International estimated these costs for 2015 to total 818 billion dollars (*World Alzheimer Report 2015: The global impact of dementia: an analysis of prevalence, incidence, cost and trends*). However, there are few national studies regarding the cost of Alzheimer's disease and related disorders in the Mediterranean area. Only regional estimations exist (southern Europe, North Africa and the Middle East). These estimations are either based on regional breakdowns by the World Health Organisation or on groupings of countries as defined by the World Bank (low-income, lower-middle income, upper-middle income and high income). Studies also exist regarding the socio-economic impact on a European level, (*Alzheimer Europe*, EUROCODE 2008). National studies in the Mediterranean deal more with specific aspects of care (hospital care, reimbursement of drugs, etc.).

It is worthy of note that a great deal of economic research is carried out to assess the cost of Alzheimer's disease and related disorders. Whether of a macro- or micro-economic nature, these studies are based on different methodologies and reference frameworks, which might explain the heterogeneous results to date.

2

DIRECT AND INDIRECT COSTS

Traditionally, the socio-economic cost of Alzheimer's disease and related disorders was divided into direct and indirect costs. The former refer both to the direct costs of medical care, (consultations, treatment, at-home treatment, hospitalisation, etc.) and the direct costs of social services. The latter are defined as lost resources; i.e. the cost of informal care, provided by family carers. However, evaluating this time raises issues. No method currently achieves a consensus (Joël, 2002). The question of taking into account this "relinquished time" is problematic. Should we consider the hourly rate that the person would have earned on the labour market or rather the average hourly rate of a healthcare professional (Stommel, 1994)? Considering intangible costs, such as patient pain or psychosocial consequences also questions the scope of the disease's impact.

SOCIO-ECONOMIC COST





QUESTION TO MARC WORTMANN

Executive Director, Alzheimer's Disease International
(United Kingdom)

In the Mediterranean region, who bears the financial burden of care for people with Alzheimer's disease and related disorders?

From the World Alzheimer reports 2010 and 2015 we know that the cost of care for people with Alzheimer's disease and other dementias is significant and increasing. Worldwide, around 20% of these costs are direct medical costs, 40% social care costs and 40% informal care costs. Informal care is mostly provided by the family. Most countries in the Mediterranean region follow this pattern, but family care costs are slightly higher in North Africa.

While they do not appear in government budgets, these costs do have an impact, for instance, when family carers lose their job it means a lower tax income for the government. For families themselves it is a huge burden as well.

Therefore, international bodies, such as the World Health Organisation (WHO) and the Organisation for Economic Cooperation and Development (OECD) point out that investing in better health care services has a positive impact on the economy of a country.

"The total estimated worldwide cost of dementia in 2015 is US\$ 818 billion. If global dementia care were a country, it would be the 18th largest economy in the world, exceeding the market values of companies such as Apple and Google"

Alzheimer's Disease International, 2015

"Dementia has significant social and economic implications in terms of direct medical costs, direct social costs and the cost of informal care"

World Health Organisation, 2015

CHALLENGES AND PERSPECTIVES

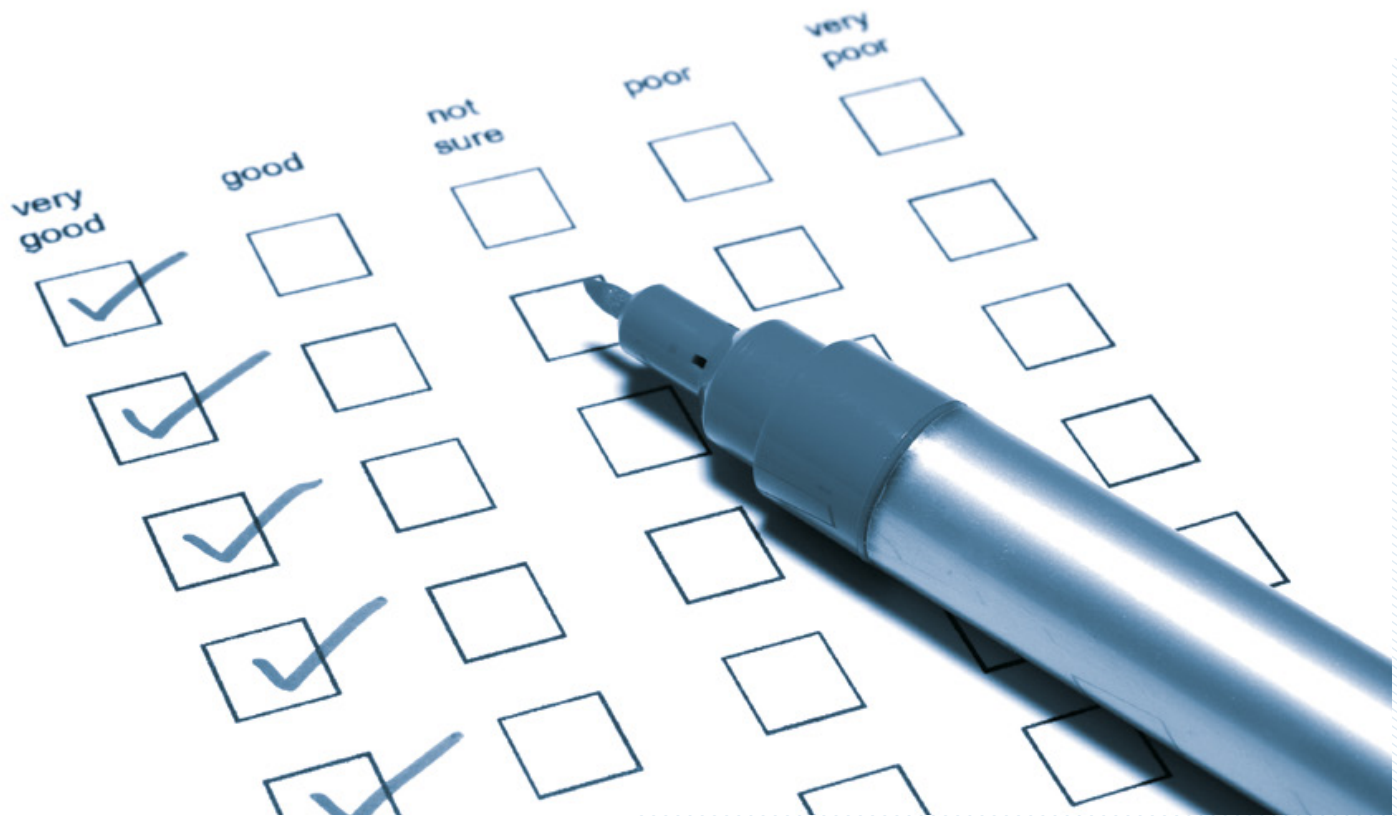
The ageing population, and the correlated and unavoidable increase in the number of people with Alzheimer's disease and related disorders and their carers will be very expensive in the Mediterranean.

It is important to carry out studies into the socio-economic impact of Alzheimer's disease and related disorders in order to create a basis for future political choices regarding healthcare reforms.

RECOMMENDATIONS

The *Mediterranean Alzheimer Alliance* calls on each Mediterranean country:

- To acknowledge the importance of the individual and collective socio-economic impact of Alzheimer's disease and related disorders
- To develop national socio-economic studies in the Mediterranean region
- To implement measures which aim to relieve the financial strain on families
- To adapt their healthcare system and implement efficient funding mechanisms



DIAGNOSIS

1

WHO ESTABLISHES THE DIAGNOSIS?

Diagnosing Alzheimer's disease requires specific training and expertise. In most Mediterranean countries, specialized doctors make this diagnosis. They may be psychiatrists, neurologists, geriatricians or specialised, multidisciplinary teams (see table hereafter).

General practitioners (GP) are rarely given the task of diagnosing Alzheimer's disease, except in Greece, Lebanon, Croatia, Malta and Cyprus.

2

A LACK OF TRAINING AMONG GPs

In most countries, the GP's role is very limited. In the majority of cases, he/she simply detects memory complaints and sends patients for a memory consultation or to see a specialist doctor for more thorough tests. Treatment often remains in the hands of specialists. However, GPs often provide care for patients after diagnosis and support them in their daily disease management.

The reason GPs play a limited role is generally due to a lack of specific training in Alzheimer's disease and related disorders.

WHO DIAGNOSES?

Algeria	neurologist / psychiatrist
Cyprus	neurologist / psychiatrist / geriatrician / general practitioner
Croatia	neurologist / psychiatrist / general practitioner
Egypt	neurologist / psychiatrist / geriatrician
France	neurologist / psychiatrist / geriatrician
Greece	neurologist / psychiatrist / general practitioner
Italy	neurologist / psychiatrist / geriatrician
Lebanon	neurologist / psychiatrist / geriatrician / general practitioner
Malta	neurologist / psychiatrist / geriatrician / general practitioner
Morocco	neurologist / psychiatrist / geriatrician
Monaco	neurologist / psychiatrist
Portugal	neurologist / psychiatrist
Slovenia	neurologist / psychiatrist
Spain	neurologist / geriatrician
Tunisia	neurologist / psychiatrist / geriatrician
Turkey	neurologist / psychiatrist

3

DIAGNOSIS CENTRES TO BE DEPLOYED

Diagnosis centres for Alzheimer's disease and related disorders exist in all Mediterranean countries. In Italy and in Spain, diagnoses are carried out respectively at the Alzheimer Unit Evaluation and private diagnosis and treatment centres. In Portugal and Malta too, there are memory centres and specialised clinics. In Croatia, there are several specialised centres and one reference centre in Zagreb. In Cyprus, patients can contact the Cyprus Institute of neurology and genetics. In Turkey, there are specialised diagnosis centres, usually located within hospitals. In France, patients can go to Memory Consultations and Resource and Research Memory Centres. In Monaco, anyone over 60 may contact the gerontological coordination centre for testing or go to the Centre Rainier III memory centre. These diagnosis centres are often connected to the country's main hospitals.

Nonetheless, in some countries, these centres are very limited in number and are unevenly distributed throughout the country. Morocco, for example, only has three memory centres (Rabat, Casablanca and Marrakech). This lack of structures leads to unequal access to diagnosis, care and support for patients. These institutions are not always public and are sometimes financed by the private sector.

4

RECOMMENDATIONS FOR DIAGNOSIS DISCLOSURE TO BE MORE FORMALISED

Only a few countries have diagnosis communication protocols: Italy, Portugal, Tunisia, Slovenia and France. In Italy, a document was drawn up by the Italian Association of Psychogeriatrics on the process by which a diagnosis should be communicated to patients and their families. In Portugal, the general rules for communicating diagnoses are set by law (Portuguese Penal Code and the Deontological code for doctors) but are not specific to Alzheimer's disease. In Slovenia there are recommendations on diagnosis communication, drawn up by specialist doctors. In Tunisia, these recommendations are made by neurologists and the faculty of medicine. In France, the *French National Authority for Health* published a recommendation on the subject in December 2011: *Alzheimer's disease and related disorders: diagnosis and treatment*.



QUESTION TO NINOSLAV MIMICA

MD, PhD, Professor of Psychiatry, School of Medicine, University of Zagreb, President of Alzheimer Croatia (Croatia)

Early/timely diagnosis of Alzheimer's disease is crucial. Can you please explain why?

Early diagnosis of Alzheimer's disease has a very positive influence on the patient's life after diagnosis. The earlier the diagnosis, the better the overall outcome will be.

Alzheimer's disease is a chronic disease and its natural course is progressive. With the worsening of symptoms, patients require more outside support and care. It is crucial to be able to plan for one's future and prepare to face these major hurdles.

What are the benefits of early/timely diagnosis?

People who receive early/timely diagnosis have a better quality of life than those who receive late diagnosis or those who are never diagnosed. For example, standard pharmacological treatments have more effect in early stages of disease and innovative therapies (new anti-dementia drugs) are often tested on people in the early-stages of the disease.

To conclude, people who receive an early diagnosis are more able to plan their future as they wish, and to make important decisions on their own, particularly regarding their end-of-life. A good diagnosis means a diagnosis made as early as possible and it is highly likely that this will occur earlier and earlier given the scientific developments surrounding diagnosis methods.



QUESTION TO MYRIEM ABADA-BENDID

Head of Neurology Service, Specialised Medical Centre of Ben Aknoun (Algeria), President of "Association Sportive des Médecins du Grand Alger" (ASMGA) Alzheimer Club (Algeria)

As a neurologist, do you think the international tools available to diagnose people with Alzheimer's disease and related disorders are adapted to the cultural specificities of the Mediterranean?

Our Mediterranean countries have a unique way of dealing with Alzheimer's disease, due to an education based on religion and traditions. The elderly person is the anchor of the family. Memory disorders are usually considered a normal part of ageing. Alzheimer associations have enabled us to raise awareness regarding memory complaints. The memory consultations carried out in university towns were the first step toward better care for people with Alzheimer's disease in our countries.



QUESTION TO MIRNA MNEIMNEH

Executive Director, Alzheimer's Association Lebanon (Lebanon)

Your association recently launched a programme concerning the early diagnosis of Alzheimer's disease in Lebanon. Could you describe this initiative in broad terms?

In Lebanon, studies estimate that less than 25% of people with Alzheimer's disease and related disorders have been diagnosed. The majority of these people live in rural parts of Lebanon. In these geographical areas, Alzheimer's disease is often perceived as a normal consequence of ageing and the illness is stigmatised, resulting in delayed access to diagnosis and inadequate care.

In this context, the Alzheimer's Lebanon association launched the "early diagnosis programme", in partnership with the Ministry of Social Affairs. This project had two aims: early detection of Alzheimer's disease among people aged 65 and over throughout Lebanon, and improved quality of life for Alzheimer's patients and their families.

One-day screening drives took place in nine regions of Lebanon, spearheaded by specialist doctors, occupational therapists and social workers. After a thorough patient assessment and confirmation of an Alzheimer's diagnosis, social workers ensured follow-up for patients thanks to a tool kit offered to carers, a telephone help line and information about drugs, which are provided by the Ministry of Health.

During the nine diagnosis sessions taking place in these areas between 2013 and 2014, 656 people aged 65 and over were examined. 107 cases of Alzheimer's disease and related disorders were diagnosed. 16% of participants were non-diagnosed and even their families were unaware that they were displaying symptoms.

The neuropsychological assessment remains the main obstacle, as it is difficult to adapt international neuropsychological tests to a heterogeneous population with significant illiteracy. In Algeria, we mainly use visual tests, such as the DMS4 (currently in the process of validation), which has proven to be a good diagnosis tool.

Our approach to diagnosis aims to be in line with our Mediterranean temperament, under the motto "humour and derision", in order to play down and de-stigmatize Alzheimer's disease. We are currently working on a global cognitive efficiency test, which plans to be ecological and fun and which draws inspiration from everyday life activities, in tune with our local population.

5

INADEQUATE TOOLS FOR DIAGNOSIS

Several tools help doctors to establish a diagnosis at increasingly early stages of the disease:

- Neuropsychological assessments (“memory tests”) which identify significant impairments (particularly episodic memory impairments)
- Cerebral neuro-imaging (MRI or CT Scan) which identifies atrophy of the internal temporal structures (hippocampus)
- Metabolic profile specific to positron emission tomography (PET)
- Modification of biomarkers in the cerebrospinal liquid (CSF)

Diagnosis is based upon tests of cognitive functions and medical imaging, as well as the development of various losses over time which are thus identified. It calls for specialised centres, with a significant technical capacity; something which can be problematic depending on the patient's geographical location. A major factor in combatting this disease is however to make a reliable diagnosis, so that patients and their entourage can receive swift and adequate support.

In the Mediterranean area, these tools, when available, are not always appropriate to the specificities of each country. An example is the problem of illiteracy (see interview with Professor Myriem Abada).

“As set out in our strategic plan, we believe that every person living with dementia has the right to a timely diagnosis and the right to access quality post diagnostic support”

Alzheimer Europe, 2015

CHALLENGES AND PERSPECTIVES

It is considered that an early/timely diagnosis of the disease enables care to be optimised. While this diagnosis requires technical expertise, the GP's role should not be minimised; particularly as regards detection, guidance and follow-up for patients and their families.

Patient access to diagnosis is of course dependent on the equal distribution of centres offering guidance, diagnosis, information and care throughout the country.

The relative absence of national recommendations regarding diagnosis disclosure can lead both to poor guidance and information for patients and their families, and a lack of harmonised professional practices.

RECOMMENDATIONS

The *Mediterranean Alzheimer Alliance* calls on each Mediterranean country:

- **To promote early/timely diagnosis for people with Alzheimer's disease and related disorders**
- **To organise an optimal territorial network of centres offering diagnosis, guidance, information and follow-up care for patients and their families**
- **To train GPs in the specificities of Alzheimer's disease and related disorders**
- **To incorporate specific training on Alzheimer's disease and related disorders in medical school programmes**
- **To encourage the adaptation of international diagnostic tools to cultural specificities**



CARE AND SUPPORT

1

UNEQUAL ACCESS TO HOME CARE SERVICES

Home care services exist in all Mediterranean countries. However, what varies from country to country is the range of services on offer. In some countries, such as France, Portugal, Monaco and Slovenia, home care services are very comprehensive, offering home help, shopping, meal delivery, nursing care, hygiene care, occupational activities and physiotherapy. In other countries, services concentrate either on care (for instance in Lebanon), or on home-help services (for instance in Malta). However, despite a few exceptions, such as Monaco and France, home-based care is very rarely suited to the specificities of Alzheimer's disease and related disorders and unequally distributed throughout each country.

Furthermore, these services are provided either by the private sector, by the public sector or sometimes by both. Care provided by the state varies significantly from country to country.

2

INSTITUTIONAL HEALTHCARE SUPPLY UNEQUALLY DISTRIBUTED AND NOT SPECIFIC TO ALZHEIMER'S DISEASE

In the Mediterranean area, hospitals are largely responsible for caring for people with Alzheimer's disease and related disorders. However, this support is sometimes unsuited to the specificities of Alzheimer's disease due to a lack of services and training in age-related illness.

In parallel to health care, there are two accommodation options for people with Alzheimer's disease and related disorders in the Mediterranean area: day care and retirement homes. As regards day care, this solution does not exist in all Mediterranean countries. Where they do exist, these day care centres do not necessarily meet needs throughout the country. Concerning retirement homes, this type of care is not widespread in Malta, Portugal and Croatia and these structures are inexistent in Morocco. These structures are rarely specialised in the care of people with Alzheimer's disease and related disorders. In countries where these structures exist, there is unequal geographical distribution.

Lastly, in some countries, such as Morocco, charitable institutions replace these types of care structures.

3

EMERGING USE OF ASSISTIVE TECHNOLOGY FOR CARE IN THE MEDITERRANEAN

There are two main types of new technologies for people experiencing autonomy loss: assistive technologies and surveillance technologies.

Assistive technology comes in various forms: paging systems for emergencies, memory stimulators for taking medicines, intelligent tools to alleviate the shortcomings of cognitive impairment (inter-device communication tools), and discussion technology to combat isolation. Their use is still very limited in the Mediterranean area, particularly due to their cost, which is often high, and the fact that they are not refunded by the welfare system.

Surveillance technologies are essentially video surveillance systems, remote alarms and geo-positioning systems (such as bracelets). These devices do not exist in every Mediterranean country. When they are sold, they are generally expensive and their cost must be fully borne by the individual or their family.

However, some countries have started to develop measures to offer access to these technologies, with relatively good financing by the public services, such as Spain, Turkey and Portugal.

The use of these devices, particularly those using geo-positioning of individuals or video surveillance systems, raises ethical concerns regarding a person's consent and respect for privacy. Few legal provisions govern the use of these new technologies in the Mediterranean area. As a result, ethical thinking surrounding these issues must be envisaged.

4

UNSPECIALISED END-OF-LIFE CARE

The end of life of people with Alzheimer's disease and related disorders is little documented in the Mediterranean area. However, just like the care of patients throughout the disease, the end of life requires specific professional skills.

The role of mobile palliative care units (MPCUs) is fundamental. They are being developed in the Mediterranean area, apart from in Cyprus and Turkey, where the solution does not exist. MPCUs may be public, such as in Spain and in Italy, where they are set up respectively by the national public health system and the regional health systems. In Portugal, these are also dispensed by the departments and establishments of the national health system, through a public network: the National network for palliative care.

In other countries, they are coordinated by NGOs (Lebanon and Malta), associations (Tunisia) or are organised by volunteers (Croatia and Morocco).

In most Mediterranean countries, MPCUs are not specialised in Alzheimer's disease and related disorders.



QUESTION TO FÜSÜN KOCAMAN

Executive Director, Turkish Alzheimer Association (Turkey)

The migratory links between Turkey and Germany are very strong. What initiatives have your association and the *Deutsche Alzheimer Gesellschaft* association implemented in order to ensure care and support for Turkish migrants in Germany and German migrants in Turkey?

Turkish nationals who have immigrated to Western Europe since 1960 in the hope of finding a better quality of life are now an integral part of the European community. Today, around 5 million Turks live in Europe and 13-20% were born on European soil. 3 million of these Euro-Turks live in Germany.

Conversely, many German citizens also choose to live in Turkey, following retirement. Public records show that 78,560 Germans were living in Turkey in 2000. Some of these elderly people are likely to develop Alzheimer's disease but there are no services provided for them in their mother tongue in Turkey.

Communication is therefore a problem due to low proficiency in the host-country language, which then further deteriorates with the onset of dementia. In addition to language barriers, lack of knowledge about dementia and its symptoms, the different perceptions of dementia (an illness, a normal part of ageing, a mental illness etc.) and the stigma associated with the illness mean that people are often isolated. This frequently leads to late diagnosis and the fact that families do not seek outside help.

This is why we launched an *Alzheimer's Disease International* Twinning Programme with the *Deutsche Alzheimer Gesellschaft* in order to increase awareness and understanding of dementia in Turkish communities in Germany and German communities in Turkey. We distribute information about dementia to both parties, provide resources for service providers to assist in understanding the needs of Turkish people with dementia in Germany and identify possible communication barriers, especially regarding cultural differences.



QUESTION TO ALAIN PESCE

University Professor, Head of the geriatric services in Monaco, Princess Grace Hospital (Monaco)

Could you explain why it is important to ensure seamless care and support in the case of Alzheimer's disease?

Alzheimer's disease is a chronic and progressive disease and a suitable solution must be found for each stage of its evolution. At the early stages, care must be multidisciplinary and continuous: medical follow-up, consultation with the patient and his/her family to communicate the diagnosis, neuropsychological care, speech therapy, etc. This is easier when takes place in a single place, but can get complicated in the case of social or/and familial isolation, or a lack of access to the healthcare system.

As the disease evolves and patients lose autonomy, families find it difficult as the patient does not perceive his/her handicap. At this stage, medical interventions must be intensified by putting an emphasis on quality of life. It is possible to adapt care gradually to avoid discontinuity, which can cause disruption for people with Alzheimer's disease and discourage their families.

This is very difficult to implement when care facilities and services are fragmented and there is a lack of communication. Day care centres and coordination services are the lynchpin of the healthcare system. Ensuring seamless care that is adapted to the specificities of Alzheimer's disease provides greater security on a physical and psychological level and improves quality of life for people with Alzheimer's disease and their families.

5

CARE FOR ELDERLY MIGRANTS MUST BE CONSIDERED

Since the end of the First World War in particular, the Mediterranean basin has seen major migratory flows from the south of the region to the north. Waves of immigration have followed in close succession; leading to the current problem, in the northern Mediterranean countries, of these now ageing migrants, very few of whom having returned to their home countries.

These migrants, who have often dealt with difficult living and working conditions in their pasts, often face an earlier loss of autonomy than their peers. This raises the issue of caring for these ageing immigrants, who sometimes have Alzheimer's disease or related disorders. The language,

religious and cultural rituals, traditions and diet of these individuals are specific and therefore call to question current practices by healthcare teams.

Conversely, the phenomenon of emigration of retired people from the north to the south of the Mediterranean area calls to question the existence and tailoring of these care structures for elderly persons, and training of the host country's health care professionals.

Lastly, it is worth noting that the problem of immigrant workers employed in the personal services sector in northern Mediterranean basin countries is increasingly acute; as witnessed for example with the *Badanti* (illegal women immigrants working as carers) in Italy.

THE ISSUE OF YOUNG PEOPLE WITH ALZHEIMER'S DISEASE AND RELATED DISORDERS

Alzheimer's disease and related disorders are often associated with advanced age. However, the disease can also affect young people. Medically speaking, a person is considered to be a young patient if they are diagnosed with Alzheimer's disease or a related disorder before the age of sixty-five. Rare or hereditary forms of the disease can also affect people in their thirties.

The consequences for people with early onset Alzheimer's disease are numerous and differ from those affecting older patients. In most cases, the diagnosis is long. The doctors often think of a depression or certain psychiatric diseases before considering Alzheimer's disease. The issue of care and support for young people with Alzheimer's disease is also called into question. Retirement homes and psychiatric care units are not appropriate, nor are care structures for people with disabilities.

The disease can also have a significant impact on family and professional life, as well as on social relationships for young patients. They often have children or parents to take care of and a diagnosis is experienced as a genuine trauma which will disrupt their role and place within the family. From a social view point, the fear of other peoples' judgement and the stigma surrounding the disease, a premature exit from the labour market and the feeling of being a burden for one's entourage are all factors which bring about isolation and exclusion. So far, only France has implemented specific initiatives with this population category in mind. These issues have recently started to be considered in several Mediterranean countries, such as Malta and Italy.

CHALLENGES AND PERSPECTIVES

The issue of care for people with Alzheimer's disease and related disorders is vital, as it is important that families do not bear the brunt alone.

Care and support mechanisms adapted to the evolution of the disease are necessary to avoid shortcomings in care and ensure continuity and a higher quality of care until end-of-life.

Whether at home or in an institution, the question of specific and coordinated services offered to people with Alzheimer's disease and related disorders remains crucial.

RECOMMENDATIONS

The Mediterranean Alzheimer Alliance calls on each Mediterranean country:

- **To develop and diversify their range of services, care and support throughout the territory, in response to the specific needs of people with Alzheimer's disease and related disorders and their carers**
- **To implement person-centered and coordinated care in order to avoid a sudden discontinuity in care provided**
- **To encourage the development of services and technologies which promote the autonomy of people with Alzheimer's disease and related disorders**
- **To ensure the best possible well-being and quality of life for people with Alzheimer's disease and related disorders at all stages of the illness**
- **To take into account the specificity of individual care and support for young people with Alzheimer's disease and related disorders**



HEALTHCARE PROFESSIONALS

OVERVIEW

1

PROFESSIONS TO BE DEVELOPED

People with Alzheimer's disease and related disorders require the assistance of a wide range of professionals (from the medical, medical-social or social sector): homecare assistants; nursing auxiliaries; nurses, physiotherapists, occupational therapists, psychomotor therapists, speech therapists, chiropodists/podiatrists, GPs, geriatricians; psychiatrists, neurologists, dieticians, ophthalmologists, ENT specialists, psychologists, music therapists, art therapists; facilitators, etc.

Most of these professions exist in Mediterranean countries. However, their number and geographical distribution does not allow the specific requirements of Alzheimer's disease and related disorders to be met.

2

A GENERAL LACK OF TRAINING AMONG PROFESSIONALS

The problem in the medical, medical-social and social sectors is a lack of training among all types of professionals in the Mediterranean region.

In Morocco for example, only neurologists are trained in these diseases. In Greece, Malta and Portugal, there is no formal or obligatory training; Alzheimer's associations take it on themselves to offer training seminars about the disease. In Tunisia, nursing auxiliaries and homecare assistants are not trained in these diseases.

Geriatricians exist in all Mediterranean countries except for Greece, Slovenia, Portugal and Croatia. In Algeria, there are a few French geriatricians who have opened clinics in Algiers. Nevertheless, the training of these geriatricians, and their numbers, are limited.

We have noticed however, that training initiatives are beginning to emerge. In Egypt for example, undergraduates receive lectures on dementia and common geriatric problems. In Croatia too, after four years of specialisation in internal medicine, doctors can study for two additional years to specialise in these illnesses. In Malta, a postgraduate programme in Ageing and Dementia Studies has been launched by the University of Malta in February 2016.



QUESTION TO CHARLES SCERRI

National Focal Point on Dementia, Professor in Dementia Studies, Faculty of Medicine and Surgery, University of Malta (Malta)

Why is the lack of specific training in Alzheimer's disease for professional carers a problem in the Mediterranean?

The reasons are varied. Only a few countries in the Mediterranean region have started to address the dementia challenge through the development and implementation of dementia strategies that address the significant lack of training that exists in dementia management and care. Training of healthcare professionals is a major requisite in developing an able workforce that not only acts as a driving force in increasing awareness but also aids in achieving early diagnosis for people with Alzheimer's disease and related disorders.

Research indicates that despite the considerable drive to promote educational campaigns aimed at primary care level, dementia remains largely undiagnosed. A lack of training in recognising the early symptoms, coupled with time constraints are some of the underlying factors. Furthermore, there is a reluctance to diagnose dementia due to the unavailability of adequate screening tools. In the majority of cases, clinicians are not trained and thus feel uncomfortable in disclosing a dementia diagnosis, and when they do, they often use broad terminology.

Similarly, a lack of knowledge and skills was also reported among nursing and social care professionals. There is an urgent need to develop a multidisciplinary trained workforce that ensures the effective delivery of high quality dementia care.

Educational institutions should invest resources in developing training programmes that meet the specific needs and challenges of individual countries, promoting research initiatives that address the obstacles to early diagnosis, and in supporting the unmet needs of communities with older adults with dementia. This last issue is especially important in many Mediterranean countries.

CHALLENGES AND PERSPECTIVES

Alzheimer's disease is an illness requiring specific skills. A lack of training of healthcare professionals in the medical, medical-social and social sectors can result in a poor evaluation of cognitive performance, inadequate care and poor quality treatment, and even give rise to abuse.

In the context of the rise in the number of elderly people, the development of the geriatric and gerontological sectors can be an opportunity to create new jobs and wealth in these countries.

RECOMMENDATIONS

The *Mediterranean Alzheimer Alliance* calls on each Mediterranean country:

- To develop the relevant professions to provide care for people with Alzheimer's disease and related disorders throughout the national territories
- To train all medical, medical-social and social professionals in the specificities of Alzheimer's disease and related disorders



MEDICAL TREATMENTS AND PSYCHOSOCIAL INTERVENTIONS

1

MEDICAL TREATMENTS ARE UNEVENLY DISTRIBUTED AND REFUND MECHANISMS ARE INCONSISTENT

To date, no cure for Alzheimer's disease exists. Four drugs on the market delay the progression of certain symptoms. The generic drugs distributed in the Mediterranean area are donepezil, galantamine, rivastigmine and memantine. However, not every country has access to these four drugs. Only one of these is sold in Algeria for example.

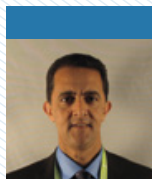
Refund mechanisms also vary from country to country. Sometimes, the drug is refunded only if a specialized doctor prescribed it. The welfare systems in Slovenia, Portugal, Italy, Spain, France and Monaco refund the four drugs available on the market. In Lebanon and Malta, only donepezil is refunded. In Egypt none of these drugs are refunded.

Regarding the prescription, in most Mediterranean countries, specialists prescribe treatments namely neurologists, psychiatrists and where they exist, geriatricians. In Lebanon, Malta and Egypt, any doctor can prescribe.

DISTRIBUTION AND REFUND OF MEDICAL TREATMENT IN THE MEDITERRANEAN REGION

	DONEPEZIL		GALANTAMINE		RIVASTIGMINE		MEMANTINE	
	sold	refunded	sold	refunded	sold	refunded	sold	refunded
Algeria	✓	✓	✗	✗	✗	✗	✗	✗
Cyprus	✓	✗	✓	✗	✓	✗	✓	✓
Croatia	✓	✓	✓	✗	✓	✓	✓	✓
Egypt	✓	✗	✗	✗	✓	✗	✓	✗
France	✓	✓	✓	✓	✓	✓	✓	✓
Greece	✓	✗	✓	✗	✓	✗	✓	✗
Italy	✓	✓	✓	✓	✓	✓	✓	✓
Lebanon	✓	✓	✓	✓	✓	✗	✓	✗
Malta	✓	✓	✓	✗	✓	✗	✓	✗
Morocco	✓	✓	✗	✗	✓	✗	✗	✗
Monaco	✓	✓	✓	✓	✓	✓	✓	✓
Portugal	✓	✓	✓	✓	✓	✓	✓	✓
Slovenia	✓	✓	✓	✓	✓	✓	✓	✓
Spain	✓	✓	✓	✓	✓	✓	✓	✓
Tunisia	✓	✓	✓	✓	✓	✓	✗	✗
Turkey	✓	✓	✓	✓	✓	✓	✓	✓

© Alzheimer and the Mediterranean Report, Mediterranean Alzheimer Alliance, 2016



QUESTION TO NAJIB KISSANI

Professor in Neurology, Head of Neurology Department, University Hospital Mohamed VI, Marrakech President of South Morocco Alzheimer Association (Morocco)

We know that drugs can treat some symptoms linked to Alzheimer's disease. In your opinion, what problems does Morocco face regarding equal access to medical treatment?

Access to this type of treatment is therefore limited to those with public or private social protection. The most deprived persons benefit from the medical assistance scheme (RAMED), based on the principles of social protection and national solidarity. Disadvantaged people can thus receive these drugs through public hospitals (when they are available) but in the majority of cases, they don't have access to them at all.

Existing Alzheimer associations, including the South Morocco Alzheimer Association, distribute generics free of charge to patients in need thanks to partnerships with certain pharmaceutical companies.

Despite efforts by the Health Ministry to develop public medical coverage in particular, Morocco shows wide disparities, both geographical and financial, in terms of access to health care. The question of equal access to drugs remains a key challenge for the future of our nation.

2

PSYCHOSOCIAL INTERVENTIONS NEED TO BE IMPLEMENTED

In the absence of a cure, non-pharmacological treatments (called psychosocial interventions) offer the possibility to improve comfort and quality of life for people with Alzheimer's disease and related disorders and their family carers. Mediterranean countries have developed a wide range of initiatives classified in the following manner (see typology hereafter):

- Therapy activities
- Activities fostering expression and communication
- Activities fostering well-being and quality of life
- Social, artistic and cultural activities
- Outdoor activities

While all of these psychosocial interventions seem to exist in the Mediterranean area, their geographical distribution is not equal in each country due to the lack of trained professionals or adapted services. We also note that the methodology and the conceptual framework of these non-pharmacological approaches vary greatly from country to country, as well as their evaluation methods.

PSYCHOSOCIAL INTERVENTIONS TYPOLOGY

	TYPE OF PSYCHOSOCIAL ACTIVITY
Therapeutic activity	Rehabilitation workshop
	Reminiscence therapy
	Art-therapy
	Cognitive stimulation therapy
Expression and support	Music therapy
	Sessions with a psychologist
	Support group
Well-being activities	Writing workshop
	Gym, relaxation, beauty treatments
Social, artistic and cultural activities	Drawing, music, games, cooking, gardening and reading
	Parties, dancing, afternoon snack time
	Multimedia activities
Outdoor activities	Excursions, walking
	Cultural tours
	Week end trips
	Holidays



QUESTION TO STÉPHANE GUÉTIN

Music-therapist, Doctor in Clinical Psychology, Université Paris 5 (France)

Can we scientifically measure the impact of music-therapy?

We are now able to scientifically measure the scientific impact of standardised music-therapy techniques. The reproducibility of identical sessions allows us to scientifically assess their impact through studies; in the same way as we evaluate the use of medication. Some studies also take into account the "treatment" effect, which can be isolated from the effect of the sessions.

The studies respect established international recommendations (the Gold Standard) concerning the method to apply when assessing non-medical treatments in order to scientifically measure the impact of music-therapy techniques.

Researchers are currently exploring the impact of each musical parameter, such as rhythm, melody, tone, etc. on the areas of the brain and our behaviour in order to decipher the mechanisms.

Can music-therapy be adapted to the cultural specificities of each Mediterranean country?

Not only it *can*, but it *must* be done. The main and indispensable quality of music-therapy is adaptation and listening, whether it be active music-therapy (based on practice) or receptive (based on listening).

Each melody and rhythm will provide a different emotional reaction, depending on culture. Using music linked to the culture and history of the patient's country is important for reminiscence and emotion. Indeed, the use of a "culturally influenced" melody allows precise autobiographic memories to resurface.

"Human and social science research is not only necessary in the absence of effective medical treatments; it is no more than a last resort in the absence of therapies allowing us to alter the progress of the disease: it is and will remain- even in the case of medical treatments- an absolute prerequisite for a global and coherent approach to disabilities associated with Alzheimer's disease and related disorders"

Bruno Anglès d'Auriac, President of the Médéric Alzheimer Foundation Executive Board, 2015



QUESTION TO MAGDA TSOLAKI

MD, PhD, Professor in Neurology, President of the PanHellenic Federation of Alzheimer's Disease and Related Disorders (Greece)

Why are non-pharmacological therapies worth developing in the Mediterranean area?

Alzheimer's disease and related disorders are chronic and progressive diseases. There are different stages of Alzheimer's disease: asymptomatic, mild cognitive impairment (MCI), early Alzheimer's disease, moderate Alzheimer's disease and severe Alzheimer's disease.

There is no medication for MCI or asymptomatic Alzheimer's disease. However, there are data in many studies confirming the effectiveness of cognitive training in MCI patients. Cognitive training is the most appropriate method to practice and enhance specific cognitive abilities, such as language, memory, and attention. Some of them have shown that cognitive training can also improve the activities of daily living.

Moreover, sensory stimulation activities, such as music therapy, acupuncture, bright light therapy and aromatherapy, have been used for different behavioural problems.

Lastly, these psychological interventions seem to have a positive impact on family carers, in terms of self-esteem, depression and anxiety.

What obstacles have been encountered to date?

There are several obstacles regarding the implementation of these psychosocial interventions. Firstly, the healthcare networks for people with Alzheimer's disease and related disorders and their families are not always well coordinated. Moreover, implementing these psychosocial interventions is expensive and requires substantial funding. It is possible to use information and communications technology (ICT) in order to reduce these costs, but elderly people are rarely aware of these ICT solutions.

CHALLENGES AND PERSPECTIVES

Ensuring equal access to treatment for all allows people with Alzheimer's disease and related disorders to benefit from up-to-date therapies and advances in research.

In the absence of a cure, psychosocial interventions, which are both standardised and assessable, constitute a significant alternative for improving quality of life for people with Alzheimer's disease and their carers, and for overcoming certain deficiencies provoked by the illness.

RECOMMENDATIONS

The *Mediterranean Alzheimer Alliance* calls on each Mediterranean country:

- To make available existing treatments for people with Alzheimer's disease under their national reimbursement systems
- To ensure equal access to treatments throughout each national territory
- To encourage the development of standardised and assessable psychosocial interventions



OVERVIEW

1

LITTLE BIOMEDICAL, FUNDAMENTAL AND CLINICAL RESEARCH ON ALZHEIMER'S DISEASE AND RELATED DISORDERS IS BEING CARRIED OUT IN THE MEDITERRANEAN AREA

Biomedical, fundamental and clinical research into Alzheimer's disease and related disorders is not currently a priority in the Mediterranean area, despite the fact that this disease constitutes a major health issue. In the Mediterranean area, the main studies currently explore prevalence, epidemiology, genetics, biomarkers, the Mediterranean diet and Alzheimer's disease, drugs amongst others.

Promoting bio-clinical research on these diseases in each Mediterranean country is a key challenge. Developing partnerships in existing public and private research centres can prove to be a tremendous economical driver and can promote excellence in these countries.



QUESTION TO MERCÈ BOADA
Scientific Director of the Fundació ACE (Spain)

The ACE Foundation occupies a major role in Spanish research. Can you describe to us the various types of research that you are carrying out (biomedical, non-medical, social, etc.)?

The Fundació ACE, launched in 1995, works in the areas of diagnosis, treatment, day care, training and information about Alzheimer's disease. It is a pioneering entity in Spain and follows the American reference model of the *Alzheimer's Research Centers of the National Institute on Aging*. Our foundation offers personalised care and full support for patients and their families.

In terms of diagnosis, each year we diagnose approximately 1,700 people and we now have clinical data registers for more than 17,000 patients. Regarding care, we boast 155 care places, with two centres open (one day hospital and one day centre), where all of our professionals offer a full psycho-stimulation programme. In terms of research, our foundation has taken part in more than 100 clinical trials and we have signed over 150 articles for scientific publications.

In terms of training and information, we have set up several initiatives addressing society, communities or specific groups (students, volunteers, media, etc.) All these activities are in line with an active approach to social responsibility, supported by our values which are excellence, passion for quality and rigour.

RESEARCH AND PREVENTION



QUESTION TO MATHIEU CECCALDI

Professor of Neurology, Head of the Neurology and Neuropsychology Department at Timone Hospital (AP-HM), President of the Scientific Council for Medical Sciences, France Alzheimer Association (France)

What are the current and future issues surrounding medical research into Alzheimer's disease and related disorders?

The issues surrounding medical research on Alzheimer's disease concern distinct time periods.

In the short term, ways must be found to attenuate the harmful effects that symptoms of Alzheimer's disease have on the lives of patients and their entourage. Whether this involves symptomatic medical treatments, non-medical "therapeutic" approaches or health care delivery models, their implementation is highly dependent on each country's medical-economic constraints and social context.

In the longer term, development of basic knowledge concerning the pathological cascade which drives "proteopathies", to take hold in the brain when neurons deteriorate, but also on a clinical level, progress in the field of neuroimaging and genetics, point to possibilities for future action on the very mechanisms of the disease.

Very soon, we will be able to slow down or even halt the evolution of brain injuries thanks to agents which specifically target the key stages of the pathological cascade.

And after that, we will prevent Alzheimer's disease by providing specific therapies at the "right moment" to subjects selected due to their high risk of developing symptoms in the near future, while they are still clinically healthy, thus allowing us to curtail the pathogenic process.



QUESTION TO PROFESSOR RIADH GOUIDER

Head of Neurology, Razi Hospital, President of the Tunisian Neurology Association (Tunisia)

You recently conducted genetic studies of Alzheimer's disease in Tunisia. What are the main lessons learned? What makes the Mediterranean population particularly interesting in this area?

Substantial advances have been achieved in the field of Alzheimer's disease genetics in recent years. The Mediterranean region has several peculiarities and should be studied extensively.

Regarding risk factors, APOE ε4 allele is now a well-established risk factor for Alzheimer's disease in our population. Its frequency has reached about 29% in Tunisian Alzheimer patients, whereas it was estimated to be 10% in healthy controls.

Concerning new mutations, a molecular genetic analysis of the recognised deterministic genes for Alzheimer's disease (APP, PSEN1 and PSEN2) was performed in Tunisian families with early onset autosomal dominant transmission of the disease. This led to the identification of a novel pathogenic missense mutation in exon 4 of the PSEN1 gene (p.I83T). However, genetic testing revealed no pathogenic mutations of these genes in a cohort of nine Tunisian families with early onset autosomal dominant transmission of Alzheimer's disease. It is worth noting that a high frequency of late onset autosomal dominant Alzheimer's disease cases was found. These findings suggest the involvement of yet unknown genes which could be transmitted according to an autosomal dominant pattern frequent in the northern Mediterranean region.

Regarding the recessive mode of inheritance, we found strong evidence that Alzheimer's disease may also be transmitted as an autosomal recessive trait, in a cohort of forty-two inbred families. Its frequency may represent 3% of Alzheimer's disease cases. This pattern of inheritance is related to a high consanguinity rate reported to be up to 29% in our population and very common in the southern Mediterranean region. Increasing our knowledge about patterns of inheritance in Alzheimer's disease could lead to the discovery of new genes specific to our population and open new prospects for a better understanding of the Alzheimer's disease pathogenesis.

"Better dementia care and a future cure require action today"
Organisation for Co-operation and Development (OECD), 2015



QUESTION TO FABRICE GZIL

Doctor of Philosophy, Head of the Study and Research Centre of the Médéric Alzheimer Foundation and facilitator for *Social Sciences for Dementia*, a multi-disciplinary research network for citizens suffering from cognitive impairment (France)

How can human and social science research help improve care for people with Alzheimer's disease and related disorders and their families?

This work is crucial for gaining an overall and coherent view of neurocognitive disorders. In particular, it helps us to:

- Analyse the consequences of Alzheimer's disease, both from a psychological point of view and from a social, legal and economic perspective;
- To come up with the best support mechanisms, whether these are non-drug treatments or healthcare measures;
- To envisage the disease in all of its complexity and to analyse all of the factors which determine patients' quality of life and autonomy.

This area of research, which was still in its infancy a few years ago, has now developed considerably. More and more researchers are now adhering to this approach. Their work allows us to better comprehend:

- The experiences of patients and members of their family and the impact of dementia stigmatisation on their experience
- The way in which patients' quality of life is affected throughout the illness and ways to improve it
- The most efficient strategies for helping family carers and professionals to face practical and ethical difficulties that they come up against on a daily basis

Faced with the complex challenges posed by Alzheimer's disease, we must draw on all of our top minds, on every discipline and on energy from every source. When carried out in a thorough and multi-disciplinary manner, human science research can contribute significantly to providing better support and greater consideration for people with Alzheimer's disease by society.

For more information: <http://www.fondation-mederic-alzheimer.org/Nos-Actions/Soutien-a-la-recherche/Reseau-de-recherche-en-SHS>

2

HUMAN AND SOCIAL SCIENCE RESEARCH MUST BE ENCOURAGED

Human and social science research covers both the work carried out in academic disciplines, (such as psychology, sociology, economics, law, philosophy, etc.) and psychosocial research carried out, for example, as part of nursing studies, rehabilitation studies or gerontology. This research, which involves together extremely varied disciplines, has been exploring Alzheimer's disease for several years and is reflecting on the social consequences of this disease.

It is worthy of note, however, that the Mediterranean area itself has not been the subject of many investigations on its own specificities regarding the social consequences of this disease. Thus, alongside biomedical research, fundamental research and clinical research, human and social science has a role to play in shedding light upon future public healthcare choices in the Mediterranean area.



QUESTION TO BRUNO VELLAS

Professor of Medicine, Head of the Gerontology Centre in Toulouse, Head of Internal Medicine and Gerontology for Toulouse Hospitals, Member of the French National Academy of Medicine (France)

You initiated a study entitled MAPT (Multi-domain Alzheimer Preventive Trial). This is a vast research initiative aimed at preventing the decline of cognitive functions in elderly and fragile people. What are its salient findings?

The MAPT study has enabled us to show the clear effect of multi-field interventions- combining physical exercise, specific cognitive exercises and prevention of vascular and metabolic risk factors- in maintaining cognitive functions as age progresses in subjects aged over 70; who are complaining of memory loss.

It thereby confirms the results of the FINGER study and moreover, it extends these results to a more elderly population and one at a greater risk of decline.

It also hints at the beneficial effect of giving a DHA supplement (omega-3 polyunsaturated fatty acids) to patients with presumably low DHA levels in erythrocytes. These results must be confirmed by further studies.

In your view, why could it be useful to develop Alzheimer prevention programmes in the Mediterranean area?

It seems vital to develop prevention trials around the Mediterranean, especially as the Mediterranean diet seems to be particularly useful in preventing cognitive decline in Alzheimer patients. This must be paired with monitoring of vascular and metabolic risk factors, and physical and cognitive exercise programmes.

3

EFFECTIVE PREVENTION PROGRAMMES

In the absence of treatment and of precise knowledge as to the origins of the disease, research has focused in the past few years, on developing prevention programmes for Alzheimer's disease and related disorders. With the risk factors for this disease now clearly identified, a promising research approach is to try to positively impact these factors in order to prevent or to delay the onset of this disease.

The Mediterranean way of life (diet, physical and social activity, well-being, quality of life, family and inter-generational solidarity, etc.) should be examined in order to develop future research programmes in the Mediterranean area.



QUESTION TO LEILA ALOUANE

Professor in Nutrition Science,
President of Alzheimer Tunisia (Tunisia)

In your opinion, how could the Mediterranean diet impact prevention and care for people with Alzheimer's disease and related disorders?

To answer this question, we must define two points: what are the staples of the Mediterranean diet and what are the probable risk factors for Alzheimer's disease.

The Mediterranean diet is rich and varied. It is made up of cereals (mainly wholegrain), pulses, seasonal fruit and vegetables, fish, olive oil, fermented dairy products, nuts and a very moderate amount of wine, without forgetting good hydration. It recommends a very limited consumption of potatoes, red meat, animal fat and sweet foods. This diet must be accompanied by regular physical activity and a healthy life-style. Its key asset is the high amount of beneficial fatty acids (oleic acid and omega 3s) which play a crucial role in preventing strokes and reducing insulin resistance. It is rich in phenols and vitamins, which provide protection from the deleterious effects of cell ageing. It also offers significant quantities of fibre, which is vital for reducing the risk of insulin resistance involved in the emergence of metabolic disorders.

The recognised risk factors of the Mediterranean diet are uncontrolled diabetes, obesity, high blood pressure and raised blood lipid levels. A good Mediterranean diet can easily regulate these factors when accompanied by regular physical activity and cessation of tobacco use. Many studies have demonstrated how the Mediterranean diet can prevent the likelihood of Alzheimer's disease and cognitive impairment. However, few studies focus on the effect of the Mediterranean diet on the evolution of Alzheimer's disease. We recommend a Mediterranean diet for Alzheimer's patients, as it reduces the likelihood of associated metabolic disorders and helps avoid or at least delay undernutrition.

"The World Dementia Council calls on all governments to significantly and rapidly increase investment in dementia research for care, treatment and prevention"

World Dementia Council, 2015

CHALLENGES AND PERSPECTIVES

Only a few Mediterranean research teams are currently exploring Alzheimer's disease and related disorders (biomedical research, clinical research and human and social sciences research). Yet, the Mediterranean countries have an important part to play in the current mobilization regarding Alzheimer research.

Besides, prevention programmes specific to Alzheimer's disease and related disorders have proved to be efficient. The lifestyle in the Mediterranean area (diet, physical and social activities, well-being, quality of life, family and intergenerational solidarity, etc.) can be a key factor for implementing prevention programmes.

RECOMMENDATIONS

The *Mediterranean Alzheimer Alliance* calls on each Mediterranean country:

- To develop specialised research teams on Alzheimer's disease and related disorders, both for biomedical, fundamental and clinical aspects and for human and social sciences
- To encourage more scientific and academic partnerships in the Mediterranean area
- To carry out more specific research initiatives for the prevention of Alzheimer's disease
- To implement a Mediterranean Observatory for Alzheimer Research



FAMILY CARERS

1

THE CENTRAL IMPORTANCE OF FAMILY SOLIDARITY

The strength of family and intergenerational solidarity, which is still particularly pronounced in the Mediterranean area, is one of the specificities behind the unity of the region. The predominant role of the family and the common cultural sense of duty with regards to elders is reinforced when the latter are vulnerable, and results in significant devotion from family members, and children in particular. Respect for elders and the obligation to assist the elderly, are prevailing values in Mediterranean countries.

The importance of religion and tradition also impacts deeply on ways in which people are cared for in the Mediterranean area. In Islam for example, the family is one of the fundamental pillars. Surah Loqman, verse 14 of the Qur'an reads: *"We enjoined upon man to be dutiful to his parents"*. Respect for elders is one of the ultimate values of this religion. In the Qur'an we read in Surah Al-Esraa verse 23-24: *"And your Lord has decreed that you not worship except Him, and to parents, "good treatment". Whether one or both of them reach old age [while] with you, say not to them [so much as], «uff,» and do not repel them but speak to them a noble word"(23). "And lower to them the wing of humility out of mercy and say, "My Lord, have mercy upon them as they brought me up [when I was] small"(24). What we call today "Alzheimer's disease" is even hinted at: "And among you is he who is taken in [early] death, and among you is he who is returned to the most decrepit [old] age so that he knows, after [once having] knowledge, nothing" (Al-Hajj, verse 5).*

These same values can be found in all other religions and cultural beliefs in the Mediterranean.

2

FALTERING SOLIDARITY WHEN DEALING WITH THIS DISEASE

Under the burden of this disease, family solidarity is starting to falter, due to recent demographic changes in the Mediterranean. Indeed, family configurations are changing, families are shrinking and becoming nuclear. Neighbourhood solidarities, although still present, are weakening, especially in big cities. Furthermore, children do not particularly wish to live under the same roof as their parents. The main carers, women, are entering the job market and are less available than before.

Alzheimer's disease and related disorders demand a great deal of availability from carers. Let us not forget that in some countries, care and respite facilities and home care services are poorly developed.

As a consequence, Alzheimer's disease can have an impact on the health of exhausted carers. Family carers are now making themselves heard ever more and are forming carers' associations.

3

A LACK OF STATUS RECOGNITION FOR FAMILY CARERS

The status of family carers is recognised by law in only a few Mediterranean countries. Tunisia and Spain are two of the few offering a special status for carers. In Turkey, once a patient is diagnosed, his/her carer is entitled to certain rights. In France, no specific status is given to the family carer, but the recent law on the adaptation of society to an ageing population acknowledges a "right to respite" for family carers, with financial support.

Carers seldom benefit from financial assistance. In Malta, however, family carers, (whether they assist a person with Alzheimer's disease or another pathology) are eligible for means-tested state benefits.

Nor are working carers recognised by law in most countries. Only a few countries have measures in favour of working carers, allowing them to support their loved one. In Italy for instance, the legal system offers carers three days off per month, paid for by their employer. In Turkey, family carers can take ten days' additional leave per year, paid for by their employer. In France, where it is estimated that 10 to 14% of employees take care of an elderly

loved one (Study on the health and well-being of employees at work, Malakoff Mederic-Sociovision, 2012), legal measures exist in their favour, such as compassionate leave and family support leave.

Moreover, while studies of family carers' health exist in the various countries surveyed, they do not focus on Alzheimer's disease and its impact. Better understanding the medical and psychological consequences of support offered by a carer, would allow us to better anticipate and identify risks for their health.



QUESTION TO STEFANIA ZLOBEC

President of Alzheimer Slovenia (Slovenia)

Alzheimer Cafés are common in northern Europe. Is this also the case in Slovenia?

Dr Bere Miesen started Alzheimer Cafés in 1997 at the University of Leyde (The Netherlands). For the first time, he invited the families of people with dementia and anyone else interested, because he found out that family members need help, information and support. The idea of Alzheimer Cafés is to organise gatherings of people with dementia, their relatives, carers, friends, dementia experts and representatives of local associations in a public place and non-medical setting, such as a bistro, café or book shop.

In Slovenia, the first Alzheimer Café was organised with Dr Aleš Kogoj (psychiatrist) and Bojanka Genorio (director of the Fužine nursing home) at Fužine nursing home on 23 June 2012. Ever since, Alzheimer Cafés have quickly spread across Slovenia, and now there are more than sixty different locations in our country.

Why do you feel that Alzheimer's Cafés should be developed in other Mediterranean countries?

At these gatherings, participants are informed and educated about dementia, exchange information and experience, talk with others and socialise. In addition to the informative and social aspect, Alzheimer Cafés have a significant role in raising awareness about dementia. There is still a social stigma surrounding dementia. We believe that Alzheimer's Cafés should be set up in all Mediterranean countries.



QUESTION TO MARIE-ODILE DESANA

President of France Alzheimer Bouches-du-Rhône (France)

Why is helping carers particularly important in the case of Alzheimer's disease?

Alzheimer's disease stands out for the deep involvement it demands from the patient's entourage. Upon diagnosis, the entire family system is affected. Many carers find that from that moment on, they are fully occupied in assisting their loved one. Remember that this disease's consequences demand round-the-clock attention from the carer, for every aspect of daily life.

In relation to the costs engendered by the disease and the shortcomings of the public authorities, carers are also obliged to contribute significantly. They are confronted with providing consequential emotional and financial assistance, likely to lead to situations of exhaustion and psychological vulnerability.

In France, the bill on the adaptation of society to an ageing population includes additional assistance for carers. Can you shed more light on these measures?

The bill is proof of greater public awareness, in that it has led to the first ever legal recognition for carers. In particular, it establishes respite assistance, in the form of a maximum allowance of five hundreds euros to finance the patient's care in respite facilities.

However, although this measure seems laudable, certain pitfalls mean that it is, in fact, inefficient: its budget is insufficient, assistance is limited to Personal Autonomy Allowance beneficiaries, there are too few facilities, etc. While things are starting to improve, there is still a long way to go before a true status for carers is recognised, along with corresponding rights.

4

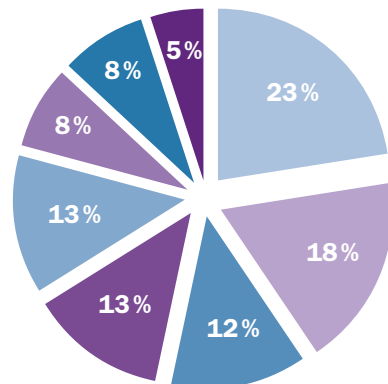
LIMITED RECOURSE TO EXTERNAL ASSISTANCE

Certain care services exist to ease carers' exhaustion. These include meal delivery, housing adaptation, treatment, assistance with daily activities and psychological support, all aiming to support carers and to relieve their burden.

Few reasons explain why in the Mediterranean region; family carers are less likely to rely on external help than in other countries.

A lack of offer as well as financial and geographical reasons, followed by a lack of information are the main causes limiting recourse to external help by carers.

© Alzheimer and the Mediterranean Report, Mediterranean Alzheimer Alliance, 2016



REASONS GIVEN BY THE SURVEYED COUNTRIES LIMITING THE RECOURSE TO EXTERNAL HELP BY FAMILY CARERS

- lack of offer
- financial reasons
- geographical reasons
- lack of information
- cultural hurdles
- lack of human means
- fear of stigma
- unawareness



QUESTION TO MARIA SELEARI

Cyprus Alzheimer Association (Cyprus)

Can you describe the action carried out by your association in order to help family carers in Cyprus?

One of the main objectives of Cyprus Alzheimer Association is to provide social and psychological support for family carers.

In order to achieve the above objective, the association organises several activities and implements relevant programmes. More specifically, the association:

- Offers programmes such as home care and companionship for people with Alzheimer's disease. Our professionals help the family carer regarding the patient's personal hygiene and housework. They also accompany patients in order to offer the carer some free-time
- Offers peer support groups for caregivers/ relatives of individuals with Alzheimer's disease, during which our volunteers offer advice
- Organises educational activities, conferences and seminars. For instance, the association is very attached to raising awareness among young people. This is why we regularly organise actions in collaboration with schools.

Raising awareness in various forms is essential in order for the general public to better understand the consequences of the disease.

CHALLENGES AND PERSPECTIVES

Family carers are crucial in supporting people with Alzheimer's disease and related disorders. Their role is even more fundamental in the Mediterranean, a region where, culturally, family solidarity is a strong cultural value. Carers are a true cornerstone and therefore must be protected, supported and recognised, in order for them to cope with their particularly difficult and complex task.

The deterioration of a family carer's state of health can have a negative impact on the care received by the person with Alzheimer's disease. Moreover, this effect is twofold, with an added risk of abuse and isolation for the carer, and an additional cost for society, constituted by the carer's deteriorating state of health.

Furthermore, the question of carers with formal employment is also set to become a subject of growing concern. The number of carers in employment (spouses or children) will increase due, on the one hand, to the rise of people with Alzheimer's disease and related disorders, and on the other hand, due to the rise in the number of working women in this region. These observations should incite companies to implement measures to support family carers.

Lastly, it is also worthy of note that some Mediterranean countries are experiencing a declining birth rate. In the future, there will be fewer children to take the role of a family carer.

RECOMMENDATIONS

The *Mediterranean Alzheimer Alliance* calls on each Mediterranean country:

- To recognise specific rights for family carers
- To develop specific support and respite measures, both medical and social (day care centres, Alzheimer Cafés, support groups, etc.)
- To implement information and counselling services (dedicated hotline, brochures, websites, etc.)
- To encourage initiatives to support working carers
- To carry out studies into the health of carers



PUBLIC PERCEPTION

1

A LINGERING PREJUDICE: A PERSISTENT NEGATIVE IMAGE OF THE DISEASE

Alzheimer's disease suffers from two myths which still linger today. Firstly, that of a disease whose symptoms can be likened to madness. Secondly, that of an illness associated with senility, which would be a natural consequence of ageing. Added to this is the fact that etymologically speaking, the French term "démence" (from the Latin, *de-mens*: loss of one's mind) was initially widely used in literature to refer to Alzheimer's disease. In Anglo-Saxon countries, the term *dementia* does not have such negative connotations as in some Mediterranean countries. In the Mediterranean, the term is still often associated with madness, and conjures up images of "mental patients" who may even be violent. This amalgam between Alzheimer's disease and madness still lingers in the Mediterranean area and most of these countries assert that the public still does not make a distinction (Italy, Tunisia, Greece, Spain, Morocco, Malta, Egypt, Cyprus, Turkey, etc.). This lack of knowledge about the disease leads to a persistent stigmatisation of people with Alzheimer's disease and related disorders.

2

PROMOTING STUDIES ON PERCEPTION, KNOWLEDGE AND EXPERIENCE OF ALZHEIMER'S DISEASE

There are very few studies on perception, experience and understanding of this disease in the Mediterranean area. Some countries have carried out studies demonstrating that the public did not know enough about the consequences of the disease, thus explaining in part the persisting negative and derogatory image. This is particularly the case in Greece, Cyprus and Malta. Other studies carried out among the general public, such as those carried out in Egypt, counterbalance this negative perception (see interview page 47).

However, there are very few studies on the perception and experience of the disease among people with Alzheimer's disease and related disorders and their carers. In France, The National Institute for Health Prevention and Education (INPES) carried out a study entitled, *Perception and Experience of Alzheimer's Patients*, which showed that despite a feeling of powerlessness and melancholy, people with Alzheimer's disease and their carers are usually optimistic and display a fighting spirit.

3

THE DISEASE'S RECENT ENTRY INTO CULTURAL AND ARTISTIC CIRCLES

Alzheimer's disease and related disorders are beginning to emerge from the shadows and are making an appearance in cultural and artistic spheres in Mediterranean countries. Exposed in full daylight, there is greater awareness and the public can now become familiar with the illness and its consequences. Whether in the form of books, testimonials, plays or films, this recurrent artistic and cultural production is leading to a certain "playing down" of the disease. In Slovenia, for example, several works have been published on the subject. In Portugal, it is the subject of a TV soap opera. In Cyprus, on the occasion of World Day, artistic projects were encouraged in the form of exhibitions and concerts. In Croatia, the Alzheimer's association has been popularising films about the disease since 2006 and exhibitions on the subject are organised for each national congress. In Egypt and in Italy, the disease entered the artistic sphere about 5 years ago through film and literature. In Lebanon, the first Alzheimer patient appeared in a TV series in 2012. In Turkey, Alzheimer's disease was recently the main subject of three movies and an exhibition was also organised.

Although this media coverage is positive, we must remain vigilant, as it can also have drawbacks. Concerning the way in which the disease is presented, we sometimes remark excesses in terms of language or metaphors associated with Alzheimer's disease and related disorders, which accentuate its catastrophic image. Moreover, could recurrent journalistic work result in information overload and "sensationalisation" of this disease?

4

PEOPLE WITH ALZHEIMER'S DISEASE SPEAKING OUT MORE AND MORE FREQUENTLY

While in northern Europe and Anglo-Saxon countries, people with Alzheimer's disease speak out reasonably frequently in public spheres (conferences, interviews, books), this phenomenon remains embryonic in the Mediterranean area. This new tendency constitutes a veritable "cultural revolution". The power of speech is transferred from carers to the patients themselves. These associations of patients must demonstrate the importance of involving people with Alzheimer's disease in implementing and considering issues and initiatives concerning them (research protocols, law bills, recommendations, etc.). For example, at a European level, the *"European Working Group of People with Dementia"* brings together people with Alzheimer's disease and draws inspiration from the *"Scottish Dementia Working Group"*. This emergence of an institutional discourse coming from people with Alzheimer's disease instead of from their carers has also more recently developed in France through "Ama Diem", the association run by Blandine Prévost, offering support to young people

with Alzheimer's disease, and the association "La vie sans oubli" run by Fabienne Piel. We notice however that this phenomenon is not yet commonplace in the Mediterranean area.

Lastly, when celebrities announce they have Alzheimer's disease it can "normalise" the illness and have a positive impact on its image. In the Mediterranean area, we have observed this in Croatia (the President of the Football Association), in Spain (the former Prime Minister, Adolfo Suarez), in Egypt (Omar Sharif, the famous Egyptian movie star) and in France (the famous actress, Annie Girardot).



QUESTION TO NABIL NAJA

Geriatrician, President of the Alzheimer Lebanon Association (**Lebanon**)

Is Alzheimer's disease still a taboo subject in Lebanon?

Since our association was set up around eleven years ago, things have changed a great deal. Ten years ago, the disease was little known by the general public, as well as by the majority of healthcare professionals. Among those who had already heard of it, Alzheimer's disease (which wasn't even considered a disease at the time) was a "problem"- a delicate subject to be handled discretely because it affected particularly intimate aspects of patients' lives. At this time, saying that someone had "Alzheimer's" was a form of infantilisation, which would lead to the person losing all of their civil rights.

Today things have changed a lot. Most Lebanese people, even those who are illiterate, or those who live in the countryside, know of the disease and are able to describe its main symptoms, (particularly deterioration of short-term memory and observable changes in a person's personality and character). They now know how important early diagnosis is for the patient's welfare.

Not only is this subject no longer taboo, but families proudly participate in the various communication drives run by our association. They regularly take part in interviews in the press and in all forms of media. A person with Alzheimer's disease has also been appointed as the disease's Ambassador in Lebanon.

Also very recently, a well-known Lebanese sportsman, whose father has Alzheimer's disease, took part in our short film to raise awareness about this illness.

What do you think would be the best way to change the image of this disease in the Mediterranean area?

I feel that the best way to alter this image in the Mediterranean area would be to forge partnerships between the various countries; in particular, via the *Mediterranean Alzheimer Alliance*. Of the common points that bring us together in the region, the social vision of the disease and family solidarity are central values.

This is why it is important to establish a common strategy for Mediterranean countries, centred around conferences on the disease aimed at the general public- particularly in schools and universities-set up by volunteers, or in partnership with town councils, activity programmes for patients and Alzheimer training for healthcare professionals, to assist patients in their homes.



QUESTION TO LAËTITIA NGATCHA-RIBERT

Doctor of Sociology, Senior Study Analyst, Médéric Alzheimer Foundation (**France**)

To what extent is the consideration of cultural specificities of Alzheimer's patients and their entourage an emerging trend in western countries?

Cultural specificities regarding Alzheimer's disease are becoming a source of growing interest. You only need to read a few headlines from recent articles in professional literature: "Gain better understanding of intercultural codes", "How to best manage inter-culturalism" "Elders from elsewhere", etc. That's why the Médéric Alzheimer Foundation has decided to conduct a study on how Alzheimer's disease is comprehended according to culture, language and the community of origin of those concerned, in France and elsewhere.

This analysis of modern literature shows that, even in France, researchers, professionals in the field, and the public authorities are now questioning culture, diversity and identity. Individuals with Alzheimer's disease, carers and family members do not necessarily have the same representations of ageing, disease or the same relationship with personal care or the same ways of comprehending family relations. This cultural diversity can represent a source of enrichment but can also sometimes imply incomprehension, tension or even "racial abuse".

This is why around the world we can observe a profusion of initiatives and original experiences, often led by associations; developing cultural skills among professionals, adapting diagnosis tools, combatting stigmatisation and providing information about the disease in different languages or adapting institutions and services for the different cultures and communities.

To find out more: <http://www.fondation-mederic-alzheimer.org>

"See the Human being and not the disease in me"

Blandine Prevost², AMA DIEM Association, 2011

² Young person with Alzheimer's disease, Founding member of the AMA DIEM association



QUESTION TO SAMIA A. ABDUL-RAHMAN

Associate Professor of geriatrics and gerontology, Ain Shams University, Founding member of the Egyptian Society of Geriatrics and Gerontology (Egypt)

For the general public in Egypt, what are the images and social representations attached to Alzheimer's disease?

Egyptians perceive forgetfulness at any age as Alzheimer's disease and being a population fond of jokes about even the negative things in life, they also joke about forgetting things, saying "I must have Alzheimer's".

This has created a tendency towards the normalisation of Alzheimer's disease, which means that people who notice the first signs of the disease often delay seeking medical advice.

A few years ago, one of the famous movie stars made a movie about Alzheimer's disease. This movie was a wakeup call for many elderly people to seek medical attention and represented a change of perspective about the disease.

Now people are afraid of getting Alzheimer's disease but nevertheless have limited awareness about the early symptoms and channels of care which are available.



The study, Evaluating Knowledge of Dementia and Alzheimer's Disease Among Egyptians,³ aimed to gauge the degree of knowledge and measure the public's lack of knowledge concerning Alzheimer's disease. 343 people were surveyed, 200 men (58.3%) and 143 women (41.7%). They all filled in a questionnaire about the nature of the illness and its symptoms.

As regards perception of the illness, this study shows that Egyptians do have correct knowledge concerning dementia. 76,6% of them know that Alzheimer's disease is a disease and not a normal consequence of ageing and 85,8% know that its prevalence increases with age. However, some prejudices are persistent. The study also demonstrates that people think Alzheimer's disease is not the most common form of dementia (66.2%), and that it is not incurable (58.7%).

Finally, this study demonstrates that there is no significant impact of age or gender on knowledge in Egypt. The factor which most influences knowledge of dementia is level of education. This raises an important issue which is that of illiteracy in Egypt. 96% of the people who were surveyed believe that the population needs more information regarding Alzheimer's disease and that the best method to inform people would be through television and TV-shows (71%). Nevertheless, Egyptian society still has limited means of disseminating this knowledge, compared with other countries in which these services are simple and readily available.

³ Sarah A. Hamza , Shereen M. Mousa , Samia A. Abdul-Rahman , Khaled M. Abd Elaziz. Evaluating knowledge of Dementia and Alzheimer's Disease among Egyptians. EJGG.2014; 1(2):1-11.

CHALLENGES AND PERSPECTIVES

Changing the public's image of people with Alzheimer's disease and related disorders is a major issue. Recent media coverage of the disease has enabled the public to become more acquainted with it. Now out of the shadows, the disease is no longer associated with negative images referring to craziness or senility.

Similarly, valuing the voices of people with Alzheimer's disease and their carers, and fostering better understanding of their experience helps to create a positive image of the disease.

Lastly, allowing people with Alzheimer's disease and related disorders to participate in the public debate encourages their social inclusion and helps change society's perception of the illness.

RECOMMENDATIONS

The *Mediterranean Alzheimer Alliance* calls on each Mediterranean country:

- To promote public awareness campaigns on Alzheimer's disease and related disorders targeted at the general public
- To develop initiatives in favour of social participation of people with Alzheimer's disease and related disorders and their families
- To carry out studies into the social representations of Alzheimer's disease and related disorders
- To carry out studies in order to better assess knowledge, perception and the experience of people with Alzheimer's disease and related disorders

Authors

Salomé Nicaise, Study Analyst, Monegasque Association for research on Alzheimer's disease (AMPA)
Federico Palermiti, Executive Director, Monegasque Association for research on Alzheimer's disease (AMPA)

Contributors

Professor Samia A. Abdul Rahman (Egypt)
Professor Myriem Abada-Bendid (Algeria)
Professor Leïla Alouane (Tunisia)
Professor Sandrine Andrieu (France)
Professor Joël Ankri (France)
Doctor Luisa Bartorelli (Italy)
Marie Antoinette Castel Tallet (France)
Professor Mathieu Ceccaldi (France)
Marie-Odile Desana (France)
Maria Do Rosario Zincke (Portugal)
Antoni Gelonch (Spain)
Jean Georges (Luxembourg)
Doctor Stéphane Guétin (France)
Doctor Fabrice Gzil (France)
Professor Emmanuel Hirsch (France)
Professor Najib Kissani (Morocco)
Fusun Kocaman (Turkey)
Marija Kušan Jukić (Croatia)
Doctor Karine Lefeuvre (France)
Sandrine Louchart de la Chapelle (France)
Professor Ninoslav Mimica (Croatia)
Mirna Mneimneh (Lebanon)
Doctor Nabil Naja (Lebanon)
Doctor Laëtitia Ngatcha-Ribert (France)
Professor Alain Pesce (Monaco)
Professor Charles Scerri (Malta)
Maria Seleari (Cyprus)
Professor Jacques Touchon (France)
Professor Magda Tsolaki (Greece)
Professor Bruno Vellas (France)
Marc Wortmann (United Kingdom)
Stefania Zlobec (Slovenia)

We would like to express our warmest thanks to all members of the Mediterranean Alzheimer Alliance.

ALZHEIMER AND THE MEDITERRANEAN REPORT 2016

Mediterranean rim countries are united by historical, geographical and cultural links, but more importantly by common values of solidarity.

In many Mediterranean countries, there is still little knowledge about the problems surrounding Alzheimer's disease, which remains under-estimated and insufficiently documented. This situation is set to have a drastic impact on health and society in years to come.

The objective of this report, conducted by the Monegasque Association for research on Alzheimer's disease (AMPA), is to gain an initial understanding of these countries' needs, to understand the measures already in place and to identify innovative initiatives in the Mediterranean region. This report will also highlight the issues and challenges for both the medical and social sectors and identify paths for reflection and action. Lastly, this report makes recommendations and call for those concerned to anticipate the impact that Alzheimer's disease and related disorders will have on the Mediterranean region in the future.

With the support of the Secretariat of the Union for the Mediterranean

MONEGASQUE ASSOCIATION FOR RESEARCH ON ALZHEIMER'S DISEASE

Europa Résidence – Place des Moulins – 98000 MONACO

Tel: +377 92 16 58 88 – Fax: +377 92 16 58 81

info@ampa-monaco.com - www.ampa-monaco.com

Twitter: @AMPAAIzMonaco – **Facebook:** ampamonaco