## FIGHT WITH STIGMA

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September 2022 is the eleventh consecutive World Month of Alzheimer's Disease, an international campaign to raise awareness about dementia. The impact of World Alzheimer's Month is growing, but the stigma and misinformation surrounding dementia remain a global problem. However, this year, more important than ever, we are talking about dementia. ADI's messages: Stop stigma. Let's talk about dementia. Supporting dementia as a priority in difficult times.

Currently, there is a lack of full knowledge about the causes of the disease, its effective treatment and prevention. That is why education, prevention, training, research and the fight against stigma are so important. We are a country with a rapidly ageing population, but there are still no specific legal conditions for people with dementia, and treatment and social care are included in the care systems for the elderly.

Alzheimer's disease is also often a taboo subject, it is stigma. The families hide that one of their relatives is sick.



They consider Alzheimer's a mental illness and it is a shame to talk about it. This is the case not only in Poland. An international poll by ADI in 2019 found that more than a third of caregivers hide from others that their family has Alzheimer's disease, and two-thirds believe the disease is a normal stage of ageing rather than a neurodegenerative disorder.

Misconceptions about the care and management of patients with Alzheimer's disease.

- Perceiving this disease as only a reduction in memory efficiency,
- It is a common judgement that since there are no effective drugs, why bother with it?
- · Confusion with depression,
- Confusing with a mental illness, stigma,
- Thinking that age is the main reason



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Therefore, in order to reduce the erroneous perception of this disease, its stigma, we proposed, as part of the Forum organised by the Polish National Health Fund, a task concerning the prevention of dementia (dementia) diseases, in particular Alzheimer's disease, consisting in education and training, as well as broadly understood health prophylaxis, stigma directed especially at people with an increased risk of developing the disease, but also at caregivers of sick people and other interested people.

September 21, 2019, was released by Alzheimer's Disease International (ADI) on World Alzheimer's Disease Day: World Alzheimer's Disease Report 2019: Attitudes towards dementia. The report reveals the largest survey to date, based on a dementia survey, compiled by nearly 70,000 people from 155 countries and territories.

The results of the world's largest survey of attitudes to dementia reveal a surprising global lack of knowledge about Alzheimer's disease, as two-thirds of people still believe the disease is a normal stage of ageing and not a neurodegenerative disorder.

The study reveals that the stigma around dementia prevents people from seeking information, advice, support, and medical help that could drastically improve their life expectancy and quality of life in relation to one of the fastest growing causes of death in the world.

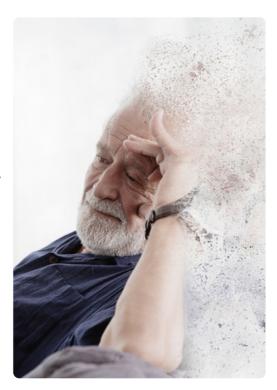
The number of people living with dementia is projected to more than triple from over 50 million now to 152 million by 2050. It is estimated that in Poland there are 370-460 thousand. patients with Alzheimer's disease, and dementia (dementia) diseases in total over 600,000.

The report reveals a surprising approach to dementia. The respondents were diagnosed with dementia, caregivers of patients, healthcare professionals and interested persons.

The main cause for concern is how many people around the world think dementia is a natural part of the ageing process. 48% of respondents believe that a person with dementia's memory will never improve, even with medical support, while one in four think there is nothing we can do to prevent dementia. These are the main barriers to accessing help, advice, and support. Stigma causes the disease to be sometimes equated with some mental health problems, focusing on age. In fact, however, there are many forms of support all over the world, and education, prevention and awareness campaigns can help people live as long as possible. Lack of knowledge and stigma are the main barriers preventing people from dramatically improving their lives with dementia.

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The report also found that around 50 percent of dementia sufferers who were surveyed felt ignored by health professionals (doctors and nurses), while 33 percent of people thought that if they had dementia they would not be listened to by health professionals or doctors. Interestingly, 95 percent of participants believe they can develop dementia later in life, and over two-thirds (69.3%) of people will take a genetic profiling test to find out if they are at risk of dementia (even if they are at risk of developing dementia). Currently there is no disease). However, two-thirds of people still think dementia is a natural part of ageing. The fear of developing dementia is high worldwide, but real understanding of the disease is low. This is worrying because Alzheimer's and other dementia diseases are the fifth largest cause of death in the world.



ADI launched its global "Let's Talk About Dementia" campaign on September 1, 2019 to mark the start of Awareness Month. The campaign is built on the understanding that talking about dementia helps combat stigma, normalises language, and encourages people to seek help, advice and support. It is estimated that in Poland there are only 18–20% diagnosed people. Currently, there is a lack of full knowledge about the causes of the disease, its effective treatment and prevention. That is why education, prevention, training and the fight against stigma are so important.

#### ADI Strategic Plan 2019-2022 - Mission

The mission for 2019-22 was to strengthen and support Alzheimer's disease and dementia associations, raise awareness, and reduce dementia stigma worldwide, make dementia a global health priority, empower dementia sufferers and caregivers, and increase investment and innovation in dementia research.



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Stigma and lack of awareness are a major problem everywhere. Worldwide, as many as 75% of people with dementia have not been diagnosed. One of the goals of the plan - Reduction of stigma. ADI will seek to reduce stigma by increasing understanding of dementia, researching the problem, recognizing cultural differences, and acting to protect the rights of people with dementia.

#### ADI aims to:

- Support the stigma issue in the 2019 World Alzheimer Report, building on existing research and research to provide the basis for future work,
- Promote understanding of dementia through World Alzheimer's Month, international conferences and regional meetings,
- Publish up-to-date information on dementia, including dementia policy,
- Support the integration of people with dementia into ADI member associations,
- Cooperate with DAI and other organisations on issues related to human rights and politics,
- Support the development of language guidelines to avoid stigma of language,
- Promote the development of dementia-friendly concepts and encourage members to support their implementation,
- Support the development of tools and programs to reduce stigma and promote their use by members and others, including intergenerational programs and education at all ages,
- Collaborate with members to increase the use of communication and social media opportunities.





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One of the main problems is the lack of support for informal caregivers who require psychological, legal, and often financial help. Carers are usually family members who often spend many years of hard work with the patient.

The problem is the fatigue and burnout of caregivers, which is caused by poor access to day and 24-hour care facilities, hospices, as well as insufficient number of trained medical and care staff.

In order to ensure an adequate level of decent illness, it is also important to allocate adequate financial resources for the treatment and care of the patient (including financing hygiene measures or lymphatic resources that have not been valorised for years), education of medical staff and educating the public about this disease. preventing stigma of the sick, and finally preparing legal regulations on prior informed choices and health checks at further stages of the disease, e.g., incapacitation, legal guardian.

Every person living with Alzheimer's (as well as with dementia) has the right to a dignified experience of the disease, and thus to:

- diagnosis as soon as possible,
- · access to high-quality support after diagnosis,
- subjective, coordinated care throughout the disease period,
- equal access to treatment and therapeutic treatments,
- the same treatment as other people in the community.

#### More materials on https://www.enso-academy.com/forum

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Zbigniew Tomczak