

OBJECTIVE 02

To promote Human Rights and
Democracy, involving citizens in policy
dialogue, design and monitoring

NEEDS AND RIGHTS OF ALZHEIMER'S PATIENTS AND RELATIVES

İzlem Sönmez

Photo: www.freepik.com



THIS ACTION INVOLVED

Establishing an Association to safeguard Alzheimers' patient rights.

Preparation and print of a report on a needs assessment study, conducted between November and December 2018, with 800 participants to identify challenges and needs of the Alzheimer's patients and relatives.

Design logo and create a Facebook page to increase the organization's visibility and outreach to target groups.

Establishment of the Alzheimer's association in May 2019. Networking with relevant civil society organisations (CSOs), including the Cyprus Alzheimer Association.

Organisation of a strategy meeting with a legal expert and a working group to develop an advocacy strategy for a legal text regulating the rights of Alzheimer's patients and relatives.

ABOUT ALZHEIMER'S ASSOCIATION

Founded in May 2019, the Alzheimer's association aims to promote the wellbeing of Alzheimer's patients by raising public awareness on the disease and related care; carrying out advocacy work to safeguard and protect the rights of patients and relatives; supporting patients as well as relatives and collaborating with relevant local and international organisations working in the same field.

STORY OF THE ACTION

The action aims to identify challenges Alzheimer's patients and relatives face and develop an advocacy strategy to encourage the improvement of essential legal texts. It also intends to make the Alzheimer's association visible as a CSO advocating the target group's rights.

İzlem Sönmez, chairperson of the association, explains the motivation of this action:

"There are no legal texts in the northern part of Cyprus acknowledging the rights of Alzheimer's patients. None of the existing legal texts refer to or include patients' rights. In fact, the current legal texts do not consider Alzheimer's patients as people with disabilities. Therefore neither can they benefit from privileges and services, including rehabilitation services, provided for people with disabilities, nor are they accepted into care homes for seniors."



Photo Credit: İzlem Sönmez

A needs assessment study was conducted with 800 individuals from Nicosia, Famagusta, Kyrenia, Morphou, Trikomo/İskele and Lefka/Lefke to identify the level of awareness on the disease and needs of Alzheimer's patients and their families.

"The most striking finding of the survey was that 97 % of respondents said they have limited or no information about Alzheimer's disease, while 94 % said they haven't got any idea about the services provided. Another important finding was that 42 % of respondents stated that they wanted to receive free home care services and 30 % of the respondents stated that Alzheimer patients' need to have fully-fledged care homes that deliver services specifically for patients through professional nurses to care for the patients."

İzlem Sönmez

The survey revealed a need for a CSO working on the rights of Alzheimer's patients. To this end, the association was established in May 2019. It developed its logo and created a social media account for visibility and outreach relevant target groups.

In light of the findings denouncing a legal vacuum to ensure the access of patients to social services, the association held a strategy meeting on 29 February 2020 with the participation of a legal expert to formulate an advocacy strategy for a specialized legal text safeguarding the rights of Alzheimer's patients and their families.

Through enhanced visibility, this action has attracted a high number of members and interest.

"The Association was hosted by 4 radio programs, 3 TV programs and featured in 8 news articles. The membership grew to 80 participants and we collaborated with the Cyprus Alzheimer's association in the Republic of Cyprus and won a Stelios Award. All this publicity contributed to raising awareness on the issue as well as igniting a public debate which we hope will continue to grow."

İzlem Sönmez

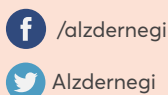
RIGHTS-BASED APPROACH

This action has promoted human rights and democracy through a rights-based approach by involving citizens in shaping public advocacy strategies and policies. The association prepared the basis for information-based advocacy by collecting data regarding the needs and situation of the target group, raising public awareness regarding the disease and the rights of Alzheimer's patients, increasing engagement of relevant professional groups on the topic, strategizing their advocacy efforts and requesting their right to be involved in the decision-making process of relevant policies and development of legal texts.

WHAT'S NEXT?

The association is committed to continuing its advocacy efforts to safeguard the rights of Alzheimer's patients. It is planning to visit policy makers to present the report's findings and encourage them to adopt a patient-oriented health policy and take actions in line with the report's recommendations.

TO FIND
MORE ABOUT
THE ACTION



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