Providing Adequate Health and Social Services to People with Dementia – Barriers and Opportunities

A report on national policies and practices in Bulgaria – Summary

Alzheimer Bulgaria Association

Introduction

Bulgaria has one of the oldest and fastest-aging populations in the European Union. According to approximations, there are 100,000 people with some form of dementia in Bulgaria, half of them suffering from Alzheimer's disease. The fast rate of ageing is highly likely to result in a rapid rise in the number of people affected by Alzheimer’s and other forms of dementia. Despite this Bulgarian government has not developed mechanisms for early diagnosis, adequate treatment and provision of care for people with dementia. The marked tendency of Bulgarian government to neglect the issue has a negative impact not only on people with dementia, but also on their relatives.

The aim of this report is to identify the main barriers to providing adequate health and social services for people suffering from dementia, as well as to propose concrete measures for overcoming them. Specifically, it pays attention to issues connected with early diagnosis, the limited provision of treatment, as well as the lack of care services. The barriers identified by the report include lack of information and awareness, insufficient political will, lack of coordination between and within institutions, underdeveloped normative framework, as well as lack of trained experts and staff.

This report builds on a range of sources, including official policy documents, two quantitative studies by Alzheimer Bulgaria Association, six round tables and the personal experience of our association with state authorities, on the one hand, and relatives of people with dementia, on the other. The objective of the first quantitative study, conducted in 2012 among 127 respondents, was to gather information on various aspects of the economic and social costs of Alzheimer's disease and other forms of dementia in the country. The second study, conducted in 2014, was a short survey on the available data and awareness, administered to 97 representatives of municipalities and social services throughout the country. The round tables were organized in six big cities in Bulgaria in the period mid 2013 – end of 2014. They gave the chance for all relevant parties (medical specialists, local government and social service representatives, relatives of people with dementia and representatives of the NGO sector) to get together and exchange information, as
well as identify specific needs, with regard to service provision for people with dementia.

**Diagnosis, treatment and care services**

According to experts, there are about 25 000 Bulgarians, a quarter of the total number of people with dementia in the country, who have not been diagnosed. This is mostly due to lack of access to and underdeveloped mechanisms for early diagnosis. People from small towns and villages have no access to specialized medical experts who are concentrated in just a few big cities. On the other hand, the general practitioners tend to view many of the dementia symptoms as normal effects of the ageing process and are not predisposed to keeping an eye out for the disease. Additionally, due to the limited number of specialists nationwide, receiving the right diagnosis can sometimes turn out not only an expensive, but also a lengthy and rather problematic process. According to the 2012 study, in one third of the cases it took longer than six months for the patients to be diagnosed correctly.

**Bulgarian health services do not offer any non-medication treatment and the condition of people with Alzheimer's or other forms of dementia is not routinely monitored.** Furthermore, the medication for hindering the development of the disease can present financial difficulties, especially for those suffering from a form of dementia other than Alzheimer's disease since their medication is not reimbursed by the state.

**Care services for people in the late stages of dementia are extremely limited and inadequate and there is no support for families who take care of people with dementia in the home environment.** There are only 14 care homes in the country, tending to 836 patients. They are understaffed (for example, one nurse is responsible for 50 patients per shift) and the personnel has not received specialized training. A recent development has been the opening up of six „family-type homes“ which provide care to 76 people in total. They have a better patient-staff ratio and generally offer better services than the state care homes.

**Main barriers**

**There are no official data on people with dementia at any of the governmental levels — central, regional or local.** Furthermore, as demonstrated by the short survey from 2014, local government and social service representatives are not informed about issues relating to dementia and Alzheimer's disease. At the same time, social workers seem to be aware of the presence of an
issue, because they have encountered it but have found themselves incapable of a proper response.

As discussed at the round tables, there is a lack of coordination at all levels. This includes coordination between and within the health and social ministries, between central and local authorities, within municipalities and between the different medical specialists — neurologists, psychiatrists and general practitioners.

National policies and the normative framework relating to people with dementia reflect the lack of information, awareness and coordination. The National Health Strategy 2014 — 2020 completely neglects the issue of Alzheimer's disease and dementia, the National Concept for Encouraging Active Life for Old People in Bulgaria 2012-2030 and the National Strategy for Long-Term Care 2014 make a brief mention of the issue without mentioning it as a priority or offering specific measures. There are two consensuses of medical specialists but they are both outdated (from 2002 and 2007) and have not been revised or employed. On the positive side, there is an upcoming National Plan for Diagnosis, Treatment and Care for Patients with Alzheimer's Disease and Other Forms of Dementia which is an important and positive step in offering an integrated approach.

Finally, there is a serious lack of trained specialists and staff at all levels — doctors, nurses, carers and social specialists. The list of official professions in Bulgaria does not include carers for people with dementia. The training for regular carers does not include knowledge and skills for working with people with dementia. Furthermore, no university in the country offers a study program in Gerontology.

Recommendations

An integrated and adequate approach to offering proper health and care services to people with dementia necessitates: data collection and dissemination; developing the normative framework; providing sufficient financing to implement the formulated measures; changing the attitudes among the relevant governmental services and institutions towards a more pro-active and cooperative approach; developing mechanisms for educating specialists and training personnel; developing mechanisms for supporting families in their care in the home environment; introducing telemedicine and telecare for people in small towns and villages.