



6 April 2018
S2018/

Ministry of Health and Social Affairs
Division for Families and Social Services
kansliråd
Anna Gralberg
08 - 405 23 19
070 - 335 23 19
anna.gralberg@regeringskansliet.se

Long-term care and palliative care IX Session of the Open-ended Working Group on Ageing

Long-term care and palliative care IX Session of the Open-ended Working Group on Ageing

Long-term care

Sweden has a high degree of local autonomy. Social services, housing and home-based elderly care are provided by 290 local municipalities and governed by the Social Services Act. Health and medical care are provided by 21 County Council and governed by the Health Services Act. The national level manages the financial control measures and is responsible for legislation and supervision.

1.) Long-term care (LTC) is publicly funded medical and social care services that all citizens, regardless of income, insurance or other personal circumstances are entitled to, based on an assessment of the individual's needs. LTC for the elderly includes different forms of assistance in a home environment or special-housing care (such as residential care, homes for the demented/dementia units, nursing homes and similar). It includes personal care, such as help with bathing, getting dressed and in and out of bed, as well as different kinds of services, such as help with shopping, transportation and housing adaptations. LTC also includes a wide use of assistive and adaptive technologies, such as digital alarms, security cameras and sensors for reminders, which in different ways may improve elderly's well-being.

A decision taken by the local social committee concerning LTC can be appealed to an Administrative Court.

In order to be able to live an autonomous and independent life it is important for women and men in need of home help services to know the available time limit and how it can be used in the best way. Despite structured and consistent investigations including documentation conducted by local social services committees there are many older women and men who don't feel involved in the decisions made concerning their specific needs and with the aim to strengthen the participation from the individual's point of view the Government has introduced a new provision that allows the local social services committee to use a simplified decision-making process with greater involvement from the individual.

2.) Since most elderly prefer to stay in their own homes even when they need more extensive care, coordinated health care and care need to be further developed to meet the needs of frail and dependent elderly men and women who choose to live at home. In January 2018 a new legislation entered into force aiming at improving the coordination between local municipalities and county councils after a person is discharged from a hospital and in need of further health care and social care.

3,4) Staffing is a central factor that affects the quality of care. The Government has earmarked SEK 1 billion (over EUR 100 million) in 2015 and a further SEK 2 billion (over EUR 200 million) annually 2016 – 2018 to increase staffing levels in order to enhance safety and quality for the elderly in need of care. To supplement higher levels of staffing, the Government also invested SEK 200 million (EUR 20,5 million) in a training initiative geared towards basic level staff who care for the elderly and people with disabilities. The aim of the training initiative is to support the municipalities in their work to develop skills improvement initiatives for this target group.

To ensure that older women and men receive a worthy, safe and individualized care, the government has decided on a new provision on staffing in special housing for the elderly. The new provision entered into force in 2016 and clarifies that based on the individual's needs staff should be available 24 hours a day in order to promptly notify if a resident needs assistance.

Sweden has a strong tradition of national quality registers for specific medical diagnoses or conditions. They contain individualized data concerning patient problems, medical interventions and outcomes after treatments.

There are no specific registers for LTC users, but four registers collect information related to elderly care for specific conditions: The Palliative Care Registry, the Senior Alert Registry, the Dementia Registry and Behavioral and Psychotic Symptoms in Dementia Registry. These offer providers the opportunity to monitor results over time and compare their results with other providers. The Palliative Care Registry addresses those involved in end of life care. It collects information on structural inputs, such as beds and access to staff, care plan associated with end-of-care, as well as information about fatalities. In the Senior Alert Registry individual data on falls incidences, pressure sores and malnutrition are registered. The aim of the registry is to prevent health problems among the elderly at home and in special houses. The Swedish Dementia Registry aims to improve quality of diagnostics, treatment and care of patients with dementia disorders. The Swedish Registry on Behavior and Psychiatric Symptoms in Dementia aims at registering individual data on care and treatment of demented persons with behavior and psychiatric symptoms. ‘

Since 2008 user satisfaction surveys on national level measure the satisfaction of long-term care services across local municipalities and units. These surveys cover care recipients both in ordinary homes and in special accommodations for elderly. The survey generates a Customer Satisfaction Index (CSI) capturing perceived service quality.

The Elderly Guide is another government initiative to improve access to information. This web-based guide for older people and their families provides information on home help services and care at special accommodations, such as service accessibility, user involvement, staffing, training, continuity of care personnel, user independence, physician’s involvement and review of drug use (prescription and information availability). The main source of data in this guide comes from special annual surveys, user satisfaction surveys and to a lesser extent from registry data.

84 percent of the elderly express that they are satisfied with LTC, according to the nationwide survey of the elderly's perception of quality in home care and special housing conducted by the National Board on Health and Welfare in 2017.

The Social Services Act clarifies that the local social welfare committee shall provide support and assistance to victims of violence. Particular attention

should be given to women who have been subjected to violence and the welfare committee is responsible for giving them support and help them to change their situation. In 2014 the Government decided on a national strategy on violence towards elderly people in need of care and health care. Furthermore, the National Board of Health and Welfare provides different types of online training for staff working within elderly care on how to prevent, identify and support older people who are the victims of violence.

Palliative care

5-9). Measures related to palliative care are primarily offered within the framework of treatment for cancer. The National Board of Health and Welfare allocates funds to Regional Centres for Cancer treatments (RCC) on a yearly basis. 4, 7 million EUR was allocated in 2018. The RCC have developed a national care program for palliative care in the final stages of life. This program is aimed at all professionals in all different forms of care where severely ill and dying people, regardless of diagnosis, is being treated. It applies to county councils, municipalities and primary care. The long-term ambition is to integrate the approach of palliative care in an early stage of a disease. The short-term goal is to offer patients and close relatives good care during the very last days of life

The access to palliative care is uneven across the country. The National Board of Health and Welfare has therefore been commissioned with the task to design evidence-based national recommendations on how to provide for good palliative care. A good palliative care is based on the four cornerstones: symptom relief, multiprofessional cooperation, communication and relationship as well as support for related relatives. Another important principle is that everyone should receive palliative care, regardless of age and diagnosis. The primary target groups for the recommendations are decision makers in health care and social services and care professionals, such as doctors, nurses, curators and occupational therapists. The recommendations also include indicators as a tool for monitoring results in healthcare and care. Since palliative care often requires ethical considerations the recommendations stress the importance of health care and care professionals being aware of ethical principles, attitude and response, as well as the importance of providing opportunities for the staff to discuss ethical questions.