

Stiftelsen Silviahemmet: A Palliative Approach to Dementia Care

Interview with Lotta Roupe



Based on Gustav Klimt, Tree of Life, Stoclet Frieze, Lebensbaum, 1905

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Elder and Long Term Care

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Introduction

In 1996, Queen Silvia of Sweden founded Stiftelsen Silviahemmet (Silviahemmet), a foundation that provides a day care center and education in dementia care. The aim of Stiftelsen Silviahemmet is to provide the highest possible standard of living for individuals who suffer from dementia and for their relatives. The Silvia Sister education program is named after Queen Silvia and is based on a palliative care philosophy that includes four central aspects of dementia care.

The first aspect of the palliative care philosophy, control of symptoms and person centered care, involves active prevention and a focus on reducing the symptoms of dementia. The second aspect, communication and relations, addresses the importance of caregivers taking time to know the person who suffers from dementia and to create a relationship with the individual. The third aspect emphasizes the need of teamwork among caregivers and includes a focus on learning from each other about how to best deliver dementia care. The fourth aspect, support for relatives, strengthens the role of relatives and ensures that relatives achieve the highest possible life quality.

After a hiatus, Silviahemmet relaunched the Silvia Sister dementia education program, in 2004, in cooperation with Sophiahemmet University College. Sophiahemmet University College is an institution of higher education for nurses and assistant nurses. The Silvia Sister course is provided online. The course provides sixty university credits. Students must be an assistant nurse or higher to qualify for the program. After graduation, participants receive the title Silvia Sister from Queen Silvia.

Silviahemmet certifies homecare organizations and delivers courses for relatives. The director of Silviahemmet, Wilhelmina Hoffman, is also the director of the Swedish Dementia Center.¹ The role of the Swedish Dementia Center is to spread knowledge about dementia through online courses. A detailed overview of the courses offered by Silviahemmet and its partner organizations is found in the appendix.

In this interview, Lotta Roupe, an assistant nurse, Silvia Sister, and manager of the day care center of Silviahemmet, talks about the history of Silviahemmet and its palliative care philosophy. Ms. Roupe also gives an overview of the day care

center and the different courses and certifications offered by Stiftelsen Silviahemmet.

About Lotta Roupe



Lotta Roupe holds a degree in assistant nursing. Since 1976, she has worked as an assistant nurse in elderly care at group homes, for homecare services, and at nursing homes in Sweden. In 2001, she graduated from the one year education program at Stiftelsen Silviahemmet and received the title Silvia Sister. In 2002, she started to work as a Silvia Sister at Silviahemmet in Stockholm. At Silviahemmet, her main responsibility is as manager of the day care center. Ms. Roupe also teaches courses in dementia care and manages reflection sessions.

Interview

Sofia Widén (SW): Please describe the background of the day care center at Stiftelsen Silviahemmet (Silviahemmet).

Lotta Roupe (LR): Stiftelsen Silviahemmet started as a dementia care school for assistant nurses. The school invited people who suffer from dementia to spend their days at the day care center. The daily residents provided clinical experience to the assistant nurses. Over the years, Silviahemmet developed into a permanent day care center. The purpose remains the same: to spread knowledge about dementia care to improve quality of life and to provide education in the palliative care philosophy.

Silviahemmet has about eight to ten visitors every day. Silviahemmet currently serves about eighteen people, which corresponds to about one hundred seventy daily visits per month. Individuals visit the day care center up to five times a week. The day care center delivers person centered dementia care. This means that the individual, the visitor, is always the highest priority for the staff members. The work starts with an extensive review of the needs of the visitors. The schedule of activities is flexible. If visitors want to go for a walk or a run or go to the gym, the staff member will adjust. After all, the person who suffers from dementia knows best what he or she needs. There is a clear structure in the work

at the day care center. This structure is also flexible and provides room for creativity and flexibility.

SW: How do you enroll at Silviahemmet?

LR: Silviahemmet is a foundation. This means that individuals either pay out of pocket or receive funding from the local municipality through a support agent system. Most people apply for funding from their municipality. We care for many younger elderly at Silviahemmet. These younger individuals are between sixty to sixty five years of age. At the age of sixty five, you have the right to elder care. The problem is that most people that visit dementia day care centers in Sweden are older than sixty five. People who are sixty five often feel very young around people aged eighty or older. At Silviahemmet, we offer two days reserved for the young elderly, while three days are set for mixed ages.

SW: How much does it cost to enroll for care at Silviahemmet?

LR: A visit to Silviahemmet costs around one thousand Swedish kronor (around 125 US dollars) per day. This is a competitive price comparable to what other day care centers charge, but the price does not cover all costs. We also receive grants and revenues from our courses and certifications.

SW: Which types of care providers can obtain a Stiftelsen Silviahemmet certification?

LR: Care homes and day care centers can obtain certification from Silviahemmet. The certification indicates the level of knowledge of the care provider. The certification process is for anyone who works at a day care center or in a care home. Anyone from the janitor to the highest managers can complete a three day training in dementia care. The course covers aspects such as different dementia illnesses, changes in the brain, symptoms of dementia, and care strategies.

The second stage in the certification process is to choose work leaders.² The work leaders participate in an additional one day training in dementia care. The work leaders supervise the care home employees to make sure that the employees follow the Silviahemmet care philosophy.

The third stage of the certification process is to send two nurses for a three day training to become reflection leaders. We hold the training either at Silviahemmet or at the care home. The reflection leaders lead monthly sessions for employees at the care home. The session lasts between one and two hours,

with the purpose of reflecting on the dementia care provided and potential improvements.

If a care home provider becomes certified at Silviahemmet, the certification is valid for three years. We evaluate the certificate after one and a half years to ensure that the care home provider is upholding the required standards. During the certification process, all participants sit a test. If the total test score of the care home is above seventy percent, the home receives the certificate. The advantage of the certification is that each individual feels strengthened in his or her role as a caregiver. As a result, each person feels more confident in his or her care approach and residents obtain better care. We can deliver each course at Silviahemmet in Stockholm or at the care home, whether that is in Sweden or abroad.

SW: Can you give an example of a work leader?

LR: A work leader could be a director or a nurse who is responsible for a department or unit. Some care providers also have assistant nurses as team leaders. A team leader has a similar function as a work leader and can attend the second stage in the certification process.

SW: Who receives the certification, the individuals or the care provider?

LR: The care provider receives the certification, not the individuals. The individuals receive a course certificate. A Silvia Sister is a person who is graduated from the Sophiahemmet University College. There is an important distinction between an individual who receives the title Silvia Sister and a course certificate from Silviahemmet.

SW: Do you evaluate your certification? What is the reaction from the participants?

LR: No. We do not evaluate our certification, but I have heard positive reactions from the participants as well from the leaders of their care units. The participants feel more confident in their roles. They collaborate better with each other. The participants are also more like to ask for help and are more secure in their image and attitude toward both visitors and relatives.

SW: Does the staff of Silviahemmet also work with the certification?

LR: Yes. I do part time education and certification, and my colleague Eva Jönsson works full time with education and certification. We also receive external help from Silvia Sisters connected to us.

SW: Do you certify international care providers?

LR: Yes. We invite international visitors to Silviahemmet. We also visit care providers abroad. I went to visit the Order of Malta³ in Germany last week. Representatives from the Order of Malta have also visited us for an instructors course. The course was a one week intensive training for instructors to learn about the palliative care philosophy of Silviahemmet. The content was more thorough than our basic courses. The instructors also learned how to convey the care philosophy to other staff members at their care homes.

SW: What type of other courses do you offer?

LR: We offer a range of courses, from shorter basic courses to longer medical trainings. The courses are either held at Silviahemmet, at Sophiahemmet University College, the Karolinska Institute, or at an external care provider.

In 2008, Sophiahemmet University College and Silviahemmet launched a degree program for nurses in dementia care. This is a one year web based distance learning program at half speed that provides thirty university credits. Four years later, we launched the first Silvia Doctor education program with the Karolinska Institute. This is a two year web based program that grants a Master's degree in dementia care. Currently, twenty five doctors are participating in the course. In November, the Karolinska Institute and Silviahemmet launched a Master's degree program for physical therapists and occupational therapists. This is also offered as an online education.

SW: Can you tell me about your palliative care philosophy?

LR: The palliative care philosophy of Silviahemmet is based on four key components. The objective of the care philosophy is to provide the highest possible quality of life for individuals who suffer from dementia and for their families.

The first component is control of symptoms and person centered care. This component involves active prevention and a focus on reducing the symptoms of dementia. If an individual starts looking for the bathroom and cannot find it, a staff member may intervene early to guide that person to the bathroom. This

intervention prevents that person from feeling confused, anxious, or frustrated because he or she cannot find the bathroom.

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The role of caring for people who suffer from dementia involves knowing the person, being able to read signals, being able to step in and provide a hand of support, but also being able to reflect carefully upon when to intervene and when to step back. There are many different illnesses of dementia, and there are equally as many symptoms. Some people lose their sense of orientation. Others struggle to express themselves. The role of the caregiver is to understand each individual and work around his or her symptoms.

The second component of the palliative care philosophy is communication and relations. To deliver person centered dementia care, every caregiver needs to take the time to get to know the person who suffers from dementia. Caregivers need to create a relationship with the individual to deliver person centered care. Caregivers do this by spending time with the individual and talking about what matters to him or her. The caregivers eat together and sit down to have coffee with the visitors. It is also important to create trust. A person who suffers from dementia must trust you.

The palliative care philosophy is not an “us and them” divide. The staff members are not viewed as caregivers, and they do not view themselves as caregivers. The staff members view themselves as friends of the visitors and communicate in that way. This is an important element of the care philosophy, especially for the younger elderly who suffer from dementia. The younger elderly do not want to be treated like patients. The younger elderly want to participate in activities and enjoy company during the day. The younger elderly need support but want to feel normal.

The third component of the palliative care philosophy is teamwork among the caregivers. Caregivers need to create relationships with each other to learn more

about how to deliver dementia care in the best way. Caregivers need to talk to each other and build relationships with other team members at the care facility. Caregivers also need to create relationships with important people in the visitors' lives, such as relatives, homecare workers, and other healthcare professionals. Caregivers need to understand that teamwork is a critical aspect of dementia care and that their team is larger than their colleagues at the care home.

The fourth and last component is to provide support for relatives. Silviahemmet invites family members to the care home, educates them, and makes sure that the wishes of family members are heard. If relatives want to be actively involved and learn about what their loved ones are doing at the day care center, then the staff members brief the relatives on a daily base. If relatives prefer to have less intensive contact with the staff, then their wishes are respected. The staff members keep a journal to make sure that they touch base with relatives at least once a month. We communicate with relatives over the phone, via text messages, emails, or other avenues. Silviahemmet strengthens the role of relatives and ensures that relatives can achieve the highest possible quality of life as well. This is a critical element in the palliative care philosophy.

SW: How do you ensure the quality of care at Silviahemmet?

LR: Every six months, we reevaluate each person's care plan and how well it is meeting the four components of the palliative care philosophy.⁴ We individualize these care plans for each individual. The care plans also serve as documentation for the local municipalities. In the care plans, the caregiver describes a range of activities an individual may like. Over time, we revise the care plan to suit the capabilities of each individual. For example, one guest may be able to take long walks and paint in the beginning of his or her visits to the day care center. After about six months, the dementia may have caused certain physical and cognitive functions to deteriorate. That individual may no longer be able to paint or take long walks. That is why the staff members continuously update and revise the care plans. Every six months, we revise each component of the care philosophy to suit the individual and his or her needs. At the same time, we hold a continuous dialogue with the individual's relatives, since the relatives may also change their minds when the needs of the individual change.

SW: What is included in the courses you provide to relatives? Are they as intensive as the courses you offer to care providers?

“I cannot tell the relatives what it is like to live with someone who suffers from dementia. Instead, relatives teach us what it is like to live with someone who suffers from dementia.”

LR: No, not really. The education for relatives is a one day course that begins to cover the brain, dementia diseases, and symptoms of dementia. During the afternoon, the relatives learn how to communicate with an individual who suffers from dementia and about the experiences of others caring for loved ones with dementia. The education for relatives involves a large component in which relatives share their experiences of caring for someone with dementia. I cannot tell the relatives what it is like to live with someone who suffers from dementia. Instead, relatives teach us what it is like to live with someone who suffers from dementia. Relatives need to exchange ideas and experiences. That is how we can support relatives.

SW: In the future, how will Silviahemmet continue to develop? Are there any changes coming?

LR: We will continue with the day care center and our courses will be held at Silviahemmet, in other parts of Sweden, and abroad. We try to plan and develop the day care center along with our visitors and evaluate our work every day after closing hours.

SW: In a larger perspective, do you think the world will be able to take care of all individuals who suffer from dementia and offer them high quality dementia care?

LR: Yes. I am hopeful for the future. Today, people arrive from all over the world to Sweden. They bring with them their culture and respect for the elderly. Swedish people must learn from other cultures how to respect older people and behave with dignity. We have the knowledge to make a change, but we also need the necessary resources. I believe the future lies in flexibility, both in resources and approach to dementia care.

SW: Thank you, Lotta, for an interesting interview.

LR: Thank you, Sofia.

Appendix: Courses Offered by Stiftelsen Silviahemmet and its partner organizations

Stiftelsen Silviahemmet (Silviahemmet) offers basic education in dementia care. These dementia courses have different target groups. There is one full day of dementia care education for anyone who interacts with individuals who suffer from dementia in their everyday life. The purpose is to describe dementia illnesses, provide strategies on how to communicate with individuals with dementia, and provide communication tools to ease the daily work. There is also a full day for relatives and a full day dementia course for homecare workers. All of these full day courses are given at Silviahemmet, outside of Stockholm.

In addition to these courses, there is a two day course in dementia care for occupational therapists and physical therapists. Silviahemmet, the Certified Physiotherapists National Council, and the Council of Swedish Occupational Therapists provide this education. The course provides a medical perspective on dementia illnesses and describes how to care for individuals who suffer from dementia. There are also individual courses that care providers can tailor for their employees. Care providers can also take a course in the palliative care philosophy in practice or living with a dementia illness.

There is a range of courses offered by Silviahemmet. The basic courses are delivered at Silviahemmet. The higher education courses are offered in collaboration with the Karolinska Institute or Sophiahemmet University College. There is a range of international professional education courses delivered through Swedish Care International.⁵ Swedish Care International shares the work of Silviahemmet with care homes and institutions abroad through a range of dementia care courses. Swedish Care International provides the possibility to Silvia Certify care homes in other countries. Swedish Care International delivers tailored courses in dementia care. Swedish Care International also collects knowledge and education in elder care from other institutions in Sweden.

In 2008, the Swedish Dementia Center was founded by the government and Silviahemmet was one of the founding members. Today, the Swedish Dementia Center is an independent foundation. The center delivers online courses, such as Dementia ABC and Dementia ABC Plus for public and professional caregivers. These courses are available to the public. The National Board of Health and Welfare finance the work of the Swedish Dementia Center.

¹ <http://www.demenscentrum.se/>

² Arbetsledare

³ Malteserorden

⁴ Genomförandeplan

⁵ <http://sci.se>



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ACCESS Health International works to help provide high quality, affordable care for the elderly and the chronically ill. Our method is to identify, analyze, and document best practices in managing the elderly and chronically ill patients and to consult with public and private providers to help implement new and better cost effective ways to care for this population. We also encourage entrepreneurs to create new businesses to serve the needs of this rapidly expanding population. At present, ACCESS Health works on these issues in high income countries, including Singapore, Sweden, and the United States. ACCESS Health is working to expand this work to low and middle income countries, including India and China.

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