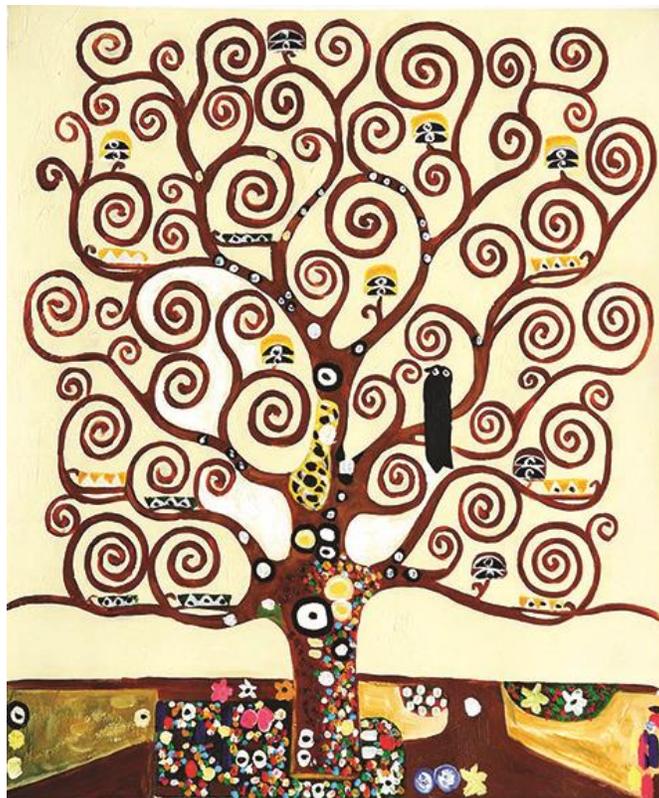




# Health of Informal Caregivers

Interview with Elizabeth Hanson

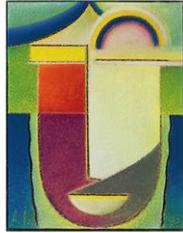


*Based on Gustav Klimt, Tree of Life, Stoclet Frieze, Lebensbaum, 1905*

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**Elder and Long Term Care**

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# Introduction: Summary and extracts of the Health of Informal Caregivers<sup>1</sup>

## The Health of Informal Caregivers

Previous research in the area of health of informal caregivers provides various explanations to caregiver health and wellbeing. Few previous studies consider the holistic experience and process of informal caregiving as key determinants of caregiver health.

### Caregiver health as an outcome process

Erlingsson et al. (2010) summarize eleven qualitative articles on the topic of caregiver health. These researchers find that the health of informal caregivers can be described as processes and outcomes of caregiver experiences. The researchers focus on subjective elements of caregiving. The experience of caregiving is a determinant of caregiver health. This captures the complex process of caring for a loved one.

Figure two illustrates the thought process of caregivers. Two different experiences lead to different health outcomes for the caregiver. When the caregiver feels supported by the formal care bodies, such as the municipality, informal caregivers remain healthy to a greater extent. Informal caregivers who perceive a lower degree of support from formal caregivers experience adverse affects on their health.

The authors emphasize the role of perception. The studies show two main concerns among the caregivers when they describe their caregiving situation. One strand of caregivers focuses on the process of caregiving. The other strand focuses on the social and elder care support system. Furthermore there are two main categories of perception within each of the groups. Erlingsson et al. (2010) uses this conceptual framework to broadly describe categories of caregivers.

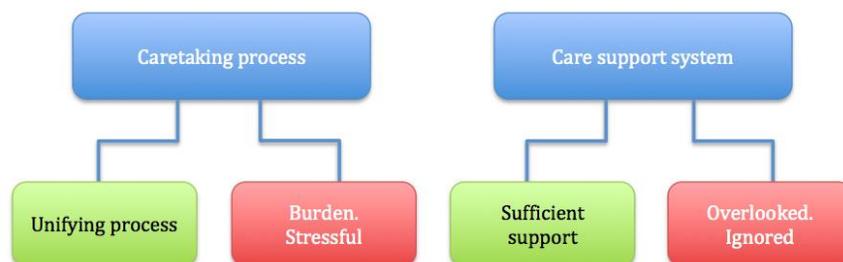


Figure one. Two main concerns for caregivers, the caregiving process versus the care supporting system

## **The situation of the informal caregiver**

The decision to become an informal caregiver is often made instinctively and is by many seen as a moral duty. Many become caregivers out of love. Others see it as a moral duty. Caregivers experience a range of feelings while caring for someone. These feelings may change over time. Many informal caregivers hold a strong belief that they will succeed in providing sufficient care. Equally, caregivers believe that they will cope well without formal assistance. Some believe that they can provide better care for their spouse, since the formal healthcare and support system only provides restricted services. Informal caregivers who live together with the person who receives care can provide flexible and accessible care.

The health of some caregivers deteriorates in the care process. Informal caregivers often attend to the needs of the person who receives care. This may include managing contacts with healthcare providers and completing all household chores that were previously a shared responsibility. Informal caregivers often try to keep up with their normal lives. The caregiver must spend a great amount of energy to ensure that daily routines go by smoothly. As a result, many caregivers feel socially isolated. Many experience high levels of stress and worry. This is why it is important to study and understand the process of informal caregiving.

The figure on the following page describes how the thought process of an informal caregiver may look like. If the caregiver feels supported by the formal care system, including the municipal care organization, the informal caregiver is more likely to remain healthy. Lack of trust in the formal support system can trigger a negative emotional spiral. This negative spiral increases the burden of caring and this explains why the health of some caregivers deteriorates.

To understand the thought processes of informal caregivers, Erlingsson et al. (2010) find that the key is to look at the conception of the caregivers. The authors categorize caregiver conceptions into separate groups based on the thought process described in figure two. The two groups include consensual caregiving and isolated caregiving. The main difference between the two groups lies in conceptions of reciprocity and unity. The first group finds support and mutuality with family and formal care personnel. However, isolated caregivers may lack these positive feelings to formal care personnel as a result of a previous negative experience. Isolated caregivers are also inclined to avoid asking family members for help as they consider that the family have their own lives to lead.

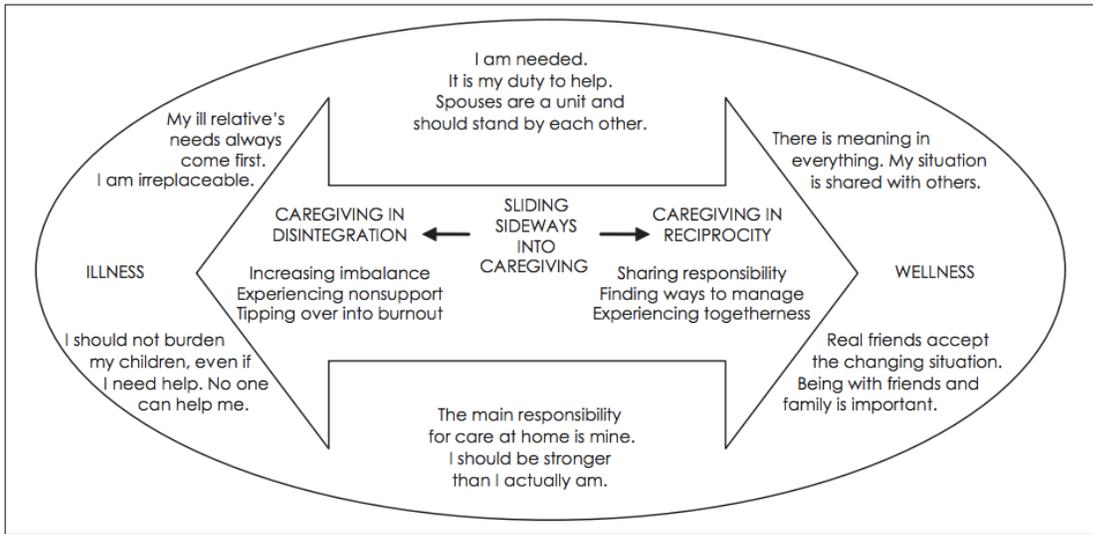


Figure two. Conceptual model of family caregivers' health: "Caregiving in a sphere of beliefs" <sup>2</sup>

## About Elizabeth Hanson



Elizabeth Hanson is a nurse and holds a doctoral degree in oncology nursing. Mrs. Hanson has worked as a clinical assistant professor in a tenure track position in Canada and as research leader in the ACTION project and associate professor at the University of Sheffield, England. At the turn of the millennium, she moved to Sweden where she is currently a professor of health care sciences at Linnaeus University, Kalmar in the south east of Sweden. Mrs. Hanson has worked in research, development work, and education within the area of care for older people and family care support. She has helped to develop innovative services for frail older people and their families. She has worked at the Swedish Family Care Competence Centre<sup>3</sup> since its inception in 2008.

**Key words:** *informal care, relatives, aging population, health of caregivers, community support.*

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## Interview

**Sofia Widén (SW):** Can you explain how you became interested in informal care?

**Elizabeth Hanson (EH):** My background is in palliative nursing care. I worked as a hospice specialist nurse. I grew up with a family perspective on care. I focus on the patient, the person, rather than the illness. In palliative care, the family is important. This philosophy has influenced my work. It has also made me interested in informal caregivers.

For the last twenty five years I have worked with people with long standing, chronic conditions and their families. I bring elements from the palliative approach to informal and chronic care. We can use this approach in dementia care, especially in advanced dementia care. Many researchers and clinicians support this approach.

By involving families in different types of care, we can improve the quality of care.

**SW:** Can you describe your philosophy to care?

**EH:** You need to look holistically at the patient, the person, not their disease alone.

Care work is multifaceted. The objective of palliative care is to address the needs of the individual and support their family. A patient may be experiencing psychological or existential pain, without any physical symptoms. You need to understand the individual to treat existential traumas.

Care work is also multidisciplinary. You need to work with a team of colleagues with different backgrounds. I have worked with medically trained staff, spiritual chaplains, social workers, and volunteers.

Ignoring family members will cause problems. It may create family conflicts. When one person is ill, the entire family suffers. Besides, the family member can undergo a lot of stress when he or she is overlooked. This may be particularly difficult during the last months prior to the death of a sick family member.

**SW:** Can you tell us about your latest publication, the *Health of Informal Caregivers*?<sup>4</sup>

**EH:** This is a literature review. It includes empirical literature, quantitative and qualitative research and theoretical work. Christen Erlingsson is an associate professor at the Linnaeus University. She led the research. We focused on older family caregivers who care for their spouse.

The literature review demonstrates that the health and the wellbeing of informal caregivers is complex. One family caregiver may carry out intensive personal care around the clock. This caregiver may still feel well. Another caregiver in a similar situation though may not feel so well. A busy mother may have a full time job and a family to take care of. To care for an older parent on top of this may in some instances prove challenging.

It is difficult to disentangle the causes and the differences in caregiver health. Subjective health status matters. Caregivers may have different health outcomes depending on how they perceive their own health. Resources also matter. We need to adapt our help to informal caregivers depending on their resilience and resources.

Caregivers cope in many different ways, which is subjective. Our study shows that deeply held beliefs about caregiving influence caregivers' wellbeing. Some perceive caregiving as purposeful. These people feel valued when they care for

their family member. These caregivers associate caregiving with meaning and status.

On the other hand, some caregivers feel that they have no choice. They assume caregiving as a duty, thrown on them. If these people were honest, they would prefer that someone else help them. They feel coerced into caring. Not everyone is suited to be a caregiver. Our research indicates that when these people become informal caregivers, their health declines. The stress of caregiving affects their wellbeing. Some experience a burnout.

The ability to ask for help also impacts on caregivers' health. Caregivers who have a network and live in a supportive community seem to be more resilient. They tend to ask for help to a greater extent. They are not scared to ask friends, family members, even if they are busy. They are not scared to ask a neighbor. They are confident to pick up the phone and ask the municipality for help.

When caregivers lack the ability to ask for help, it is more likely that they suffer. These caregivers feel that other family members have their own lives to lead. They are wary to call the municipality for help. Some may have had a prior negative experience when they ask for help. These people are totally isolated.

The ability to ask for help and perceived burden of caregiving impacts on the health of caregivers. Deeply held beliefs play a central role. If there are support services from the public sector that are appropriate, timely, and fit in with their caring routines and their preferences, then caregivers often feel better. Again, it is a complex picture!

**SW:** Tell me about caring in isolation versus caring in partnership.

**EH:** We call it caring in reciprocity. Currently, working in partnership is a popular concept in health and social care. For those carers caring in isolation it can often be very difficult for them to admit that other people can be of help in the caregiving process... that they are not on their own. Caregivers who accept help from other family members or neighbors, may ask for help with practical chores, such as cleaning the windows and the grocery shopping or sitting with their sick relative. Making a schedule can help.

**SW:** Can you talk about gender, educational, and socioeconomic trends in informal caregiving?

**EH:** There are some clear trends in informal caregiving.

Male and female caregivers over the age of sixty five care in an equal number to a greater extent. However, recent Swedish research highlights that the gender gap is narrowing with regards to working carers and carers of working age so that increasingly caring is not simply a female domain which is very important to highlight! Previous Swedish research suggests that older male spousal caregivers tend to perceive care as a job. They take it on as a task. They see it as a new and meaningful task. I am generalizing, but some older males may have little prior cooking experience. They seek advice from others. They follow simple recipes. They associate care with the tasks they performed in their working life. These male caregivers often find it easier to switch off from the caregiving role. They can relax better in the evening when their tasks are completed. Interestingly, older male caregivers obtain more support from the municipality than their female counterparts. In contrast, female caregivers show higher stress levels. They are less likely to obtain the same amount of help as male caregivers.

**SW:** What trends do you see in different ethnic groups in Sweden?

**EH:** In Sweden, this is largely a neglected area of research. In previous research, the sample sizes remain small. We cannot draw conclusions on the basis on these studies. I think previous studies tend to show that the experience or phenomenon of caring itself is also similar for carers from different cultural backgrounds; they experience challenging aspects as well as some positive aspects just the same.

Nevertheless, caregivers from ethnic minority backgrounds may not reach out as much for support to the formal sector. They may not know what kind of support there is available locally. They may rely on other family members. Thus, there may be an increased risk that they care in isolation. Practitioners explain that carers from ethnic minority groups are usually harder to reach. The formal sector may be unable to find these people and reach out to them.

**SW:** What support can a municipality offer to informal caregivers?

**EH:** The municipalities across Sweden vary in the range and prevalence of support services they offer to carers. Many organize support groups for caregivers so that they are able to meet and exchange their experiences with each other. There are now fewer municipalities that offer high intensity carers the option to be partly paid employed<sup>5</sup> to carry out their caring role. This group of carers faces a number of challenges. Clearly, the partly paid position does not cover all the hours of caring. As a result, the carer may find her or himself increasingly isolated at home and subsequently they are less likely to be able to enter the paid workforce, which in turn affects their financial situation and their

future pension. As a result, the number of municipalities that offer informal carer employment has been significantly reduced.

**SW:** How important is 'in kind' support to informal caregivers?

**EH:** The majority of caregivers across all ages, gender, and ethnic groups tend to request financial support. Many caregivers want to know what sorts of financial support is available to them. They want to know about their rights. Caregivers do not receive a large sum of money from the municipality. They may receive just a token. For caregivers it is very important to recognize the valuable role they play in society.

Unfortunately, not all municipalities provide extensive support to informal caregivers. Financial support to caregivers is often one of the items to disappear in municipal cost reduction plans. Informal caregivers reduce healthcare and social care costs. The help informal caregivers provide is central.

**SW:** Do you advocate for more informal caregiver employment in the future?

**EH:** No. I do not because for a number of informal caregivers this may not be the ideal solution for the reasons given above. We need more flexible services that suit the needs and preferences of different caregivers. Some researchers argue that services need to be adjusted to the type of caregiver, for instance a working carer or an older, retired carer. The municipality needs to deliver services in the most cost effective way. In Sweden, we need to tailor our support services to caregivers' own personal caring situation to a much greater extent.

**SW:** Can you explain how the generalization of support services to caregivers is harmful?

**EH:** We tend to think that one size fits all. In Sweden, some municipalities offer more rigid respite care support. Formal care services in those municipalities are available from Monday to Friday during work hours. What happens during the remaining hours? Care services may close down from late June, all of July and early August. Many informal caregivers carry out intensive care during this typical Swedish holiday period. They need to manage on their own whilst many other professionals are on holidays. Holiday times are challenging for informal caregivers.

However, some municipalities carry out evening and weekend services. They may have an emergency drop in. A caregiver who feels burdened can call the emergency service. Care services may be able to offer a short term stay for their older relative.

**SW:** Do you need to be a registered caregiver to benefit from that emergency service?

**EH:** The formal care services need to know you. You need to know whether the emergency facility is available or not. High intensity caregivers often greatly appreciate an available emergency care service.

The difficulty is to communicate information to the caregivers. Many individuals who could benefit from caregiving services are unknown. This is a key challenge for the support to individuals in need. The caregiving families are sometimes unaware of the options available to them.

**SW:** How can we help informal caregivers to care in reciprocity?

**EH:** This is a crucial question. First, we need to enable the caregiver to see themselves as caregivers. We need to recognize their central role.

This is important for the subjectivity of the experience as a caregiver. The caregiver should be able to feel respected in their role. They should also feel supported. It is vital that health and social care professionals actively recognize their existence. We need to offer support very early on. This support should also be fine tuned to their preferences and personality.

A great way to support care in reciprocity is to organize peer support. Caregivers often greatly value peer support. Caregivers need to know that there are other people in a similar situation to their own, that they are not alone. They can share their experiences. They receive support tips from each other. They develop their own support network.

Women often favor peer support groups. However, group situations do not suit everyone. We need to gain an understanding of how to tailor the needs and preferences of caregivers from different backgrounds and genders. This way we can support the caregivers more accurately. We can detect when caregivers begin to suffer from their role.

We tend to notice that the means to achieve support differ between men and women. I am generalizing now, but older men for instance may not always appreciate general coffee and chat or 'get together' sessions. Some older men may prefer to learn more about caregiving in a more formal educational environment. Some individuals may prefer to read a book or read online about the caregiving stories of others. Someone from the formal care services, such as a family care advocate or advisor in the municipality can help assess your caring situation together with you. This person will discuss a support strategy with you. He or she

can help empower you as a caregiver. Family care advocates or advisors may help prevent carers from caring in isolation.

**SW:** How do you help informal caregivers to know their rights and where to obtain help?

**EH:** In everyday life, caregivers who talk to friends and family share knowledge and ideas to a greater extent. For a working carer, for instance, a work colleague can be a good person to talk to. This person may be an understanding manager who has found himself or herself in a similar situation, helping to care for a sick, disabled or aged family member. Colleagues and peers can guide caregivers. They can ask caregivers if they have thought of contacting the local care municipality for support. They can ask if the informal caregivers have read brochures or booklets about caregiving. Colleagues might have useful contacts that can help you.

Of course, the local medical center is a prime place for caregivers to receive timely information. There may be brochures and tips available at the primary care center. Your local doctor, the district nurse, and the community nurse can provide information. Many people trust their doctor. You can ask healthcare professionals if they are caring for a relative on a regular basis. If so, you may proceed to ask further questions.

Then of course, in the municipality, family care advisors or advocates are able to offer dedicated support to carers and at the same time they are responsible for developing support services in the municipality. However, it is important that all staff are 'carer friendly', in particular, Needs Assessors and social workers so that they are able to recognize carers in the local community and direct them to sources of support before carers reach a crisis situation. More and more, there are good examples of Internet based information that is useful for carers such as the 'online Carer book' of Carer Sweden and dedicated online information for carers provided by not for profit organizations such as the Dementia Association and the Stroke Association. At the same time, it is important to realize that older carers may not have regular access to the Internet so that printed informational material is still important and relevant so that they are not socially excluded.

It is also important to say that the hospital can guide caregivers. For example, Uppsala University Hospital in Sweden, offers support to caregivers in the emergency care setting. They experienced that many informal caregivers accompany their seriously ill relative to the hospital emergency room. A dedicated staff member at the hospital helps the caregiver to navigate through the

hospital. This dedicated person can obtain important information from the caregiver about the care and preferences of their sick relative.

We need to creatively empower informal caregivers. We need to recognize informal caregivers in the workplace, in schools, in libraries, and at the pharmacy... in everyday life.

This recognition is critical for health and social care. This is critical for all of us within today's society to manage the challenges of demographic ageing trends and manage the public budgets.

**SW:** According to your research, is one type of support more effective than other types of support?

**EH:** We developed our research together with caregivers and older people. We worked with these individuals from the initial idea through the whole research process. Our research indicates that actively engaged informal caregivers provide invaluable support during the entire research process. Active caregivers and older individuals have helped us to develop meaningful and more responsive support services such as the ACTION service, our work with the COAT assessment tool and the use of Blended learning networks (see references below).

Effective support refers to services that are of proven value, and have no significant tradeoffs.<sup>6</sup> It has been shown from researchers in Skåne, Signé Andrén for instance, that it is important that informal caregivers of people with dementia are provided with a combination program. The combination program includes group education, psychosocial support, and skills training. The program provides practical training for caregivers' daily activities. Caregivers attend combination programs in groups, where they can share educational material and experiences.

Combination programs allow caregivers to practice cognitive strategies. Caregivers can develop a particular skill through the program. The progress of informal caregivers can be tracked with some homework type tasks. After the main training course, check up sessions are offered. Informal caregivers can attend eight or twelve check up sessions over time to maintain their skills. They can raise questions and concerns that may develop over time. These check ups help those carers who wish to continue caring to be able to do so.

**SW:** What policy changes should we implement in informal care?

**EH:** Policymakers worldwide need to develop appropriate legislation for informal caregivers. This type of legislation needs to cut across different

departments of the government. Healthcare, employment, finance, insurance, and pension policies all impact informal care. Policy changes that affect more than one area are complex to implement.

In Sweden, healthcare policies need to provide more specific legal recognition concerning informal caregivers. The Social Services Act<sup>7</sup> already recognizes informal caregivers in social care. We need to extend the recognition of informal caregivers in the healthcare policies, and beyond.

In Sweden, we have a strong welfare state. Other countries, such as the United Kingdom, do not offer the same level of social protection. Countries need to rethink how they can integrate informal care with other types of care. We need to enable informal caregivers of working age to coordinate informal care with a career. Combining paid work and care should not affect the caregiver's current salary, neither should it adversely affect her or his future pension and neither should it impact negatively on their own health and wellbeing.

Lastly, we need to combine education and informal care. Young informal caregivers tend to enjoy a lower formal educational status. Once young informal caregivers enroll in a university degree, they are less likely to complete a degree, compared to young individuals who are not informal caregivers. How can educational policies support young adults who wish to combine studies and informal care? We need to think about how we can best support young informal caregivers to complete university degrees.

I am actively involved with Eurocarers,<sup>8</sup> a European not for profit organization. Eurocarers comprises national caregiving organizations and national research organizations. Our policy experts, such as Stecy Yghemonos and Christine Marking, advocate for the need to include a clearer and stronger carer perspective within a range of European policies. We are constantly looking for inroads into specific policy initiatives to ensure that the voice of informal caregivers is heard and acted on. A current priority is work life balance and a focus on working carers and carers of working age.

**SW:** Does the welfare state crowd out informal caregivers in Sweden?

**EH:** There are diverse theories on the subject. I find it unlikely that the welfare state will crowd out informal caregivers. Caregivers are an integral part of all societies. Caring is part of the natural fabric of life and relationships.

Back in the 1970s, when the welfare state was thriving in Sweden, there were many family caregivers. At this point, the welfare state did not crowd out informal caregivers. Is informal caregiving a persistent element of society? I

believe informal caregiving is at the heart of relationships. When you are in a relationship with someone who becomes ill or who develops a disability, you often want to support your loved one. For this reason, informal caregiving remains an important component of all societies.

The welfare state remains an invaluable source of support. I believe the welfare state and informal caregivers need to work in partnership. The informal caregivers can choose to what extent, if any, they want to or are able to care for their relative. A child may be able to help his or her parents take medicines or do the groceries. A child may be reluctant to help the parents with more intimate caregiving tasks, such as showering. This is where the formal and informal sectors can work together.

In many European Union Member States, informal caregivers often lack options. Most informal caregivers must carry out all caregiving tasks, where the welfare state is absent. In some Member States adult children even have a legal responsibility to take care of their sick or disabled parents. Few family members are able to afford to pay for caregiving services.

**SW:** How would you describe the ideal support to family caregivers?

**EH:** The ideal support to family caregivers is individualized support that suits the needs and preferences of the informal caregiver. Ideal support is flexible. It foresees and adapts to evolving care circumstances, including the illness or disability trajectory. Formal support needs to adapt to all phases of care, from the early stages to the end. Formal care does not end with the death of the individual. Giving post care support to caregivers during the bereavement period is equally important.

The core of the formal support should be geared at information, advice, education, and support. Support can be emotional, in particular for those who carry out intensive amounts of care. Support can also be practical, such as respite care. Respite care includes when someone comes to your house and assumes responsibility for a few hours so that you can go out. Public care organizations, welfare services, family members, and voluntary organizations can deliver these types of support.

In Sweden, I think that public and voluntary sector partnerships will define the future of informal care. This is where local and community partnerships can come to fruition.

**SW:** What trends do you observe in Sweden?

**EH:** Our previous coalition government initiated some interesting developments. The government implemented the Freedom of Choice Act.<sup>9</sup> This Act allows individuals to choose their formal health and social care provider. In theory, this measure gave access to a wider pool of potential support so that older individuals were able to choose from a wider pool of care providers. However, this was easier in larger towns and cities than on the countryside.

The Act also carries some downsides. Research from the University of Stockholm showed that older individuals with more formal educational qualifications are more likely to afford private healthcare. Older individuals with less formal education are more likely to rely on family members. They cannot afford private care. This research demonstrates clear socioeconomic differences in care accessibility. This is a worrying trend in terms of the 'haves and the have not's' in our society.

**SW:** Does this trend impact health outcome of informal caregivers?

**EH:** Precisely. As a result, family caregivers with less economic resources receive limited formal support. Sometimes, the older individual does not want personal care from their family members. We forget this aspect. These individuals may prefer to receive intimate care from formal care providers. These individuals sometimes lack the resources to pay for private help.

**SW:** Would society cope without informal caregivers?

**EH:** Society would struggle. This is why we need to recognize informal caregivers better. They have a central role in our society. Municipalities struggle with yearly budget restrictions. Municipalities assume that there is little room for manoeuvre. They often fail to see the long term investment of preventive strategies. Investing in informal caregivers is a preventive strategy.

In the field of information and communications technologies, telehealth and telecare can help to ease the situation somewhat. Telecare generally refers to technology that allows individuals to stay safe and independent in their own homes. Telecare differs from telemedicine and telehealth. Telehealth is similar to telemedicine, but includes a wider variety of remote healthcare services beyond the doctor patient relationship, usually by nurses, social workers or pharmacists.<sup>10</sup>

Telecare and telehealth have great potential to support informal caregivers. We can use these technologies in prevention. We can Skype with caregivers and support them remotely. We can use technology to maintain active lifestyles. We

can incorporate technologies in caregiving to lift the burden of care. Municipalities need to invest in technologies for the future.

Not until an informal caregiver suffers from a burnout does the municipality realize that family caregivers need support. Although our research suggests that effective care requires timely provision of support, early on. We need to prevent burnouts.

We need to enable preventive approaches to care. Preventive care supports the health and the wellbeing of both the older individual and the informal caregiver. This way, we avoid one patient turning into two. We will have healthier patients and informal caregivers who feel valued. Preventive measures are critical.

**SW:** Can you describe the determinants of health of informal caregivers?

**EH:** Caregiver resilience is a health determinant. The perception of caregiving is another determinant. In our studies, we see a tipping point. Once you cross this tipping point, the health of the caregiver is affected. As a caregiver, you should do what you feel is comfortable. You should perform tasks that integrate with your life balance. An imbalance occurs when care becomes difficult to handle, and when you are unable to seek help. You will feel pressured and stressed. You will arrive to work demotivated. You arrive late to work. You start resenting your tasks. These are the signs of a burnout. This is when the caregiver is at risk of developing ill health her or himself.

**SW:** How many people are informal caregivers?

**EH:** In Sweden, there are at least one million and three hundred thousand informal caregivers. This is approximately ten percent of the total population of Sweden. The vast majority of these caregivers, nine hundred thousand individuals, pursue a career simultaneously. Typically, these caregivers are middle aged daughters and sons of aged parents.

We also know that individuals over the age of eighty perform most of the heavy caregiving tasks. This is because their relative, often their spouse, is of a similar age. At least one in four over the age of sixty five is an informal caregiver. A large number of these individuals care more than twenty or thirty hours a week. This is a full time job, which is incredible considering the age of the caregivers.

Many cope well with the heavy caregiving tasks. Some do not admit how tired they are. When an informal caregiver does not admit that the care burden may be too large, it is difficult to offer help.

**SW:** What are the differences between Great Britain and Sweden?

**EH:** The caregiving experience is similar across cultures. Informal caregivers feel that they have known each other for a long time when they meet at conferences. They share a similar experience. They understand each other. I am moved when I see this.

In the United Kingdom, I see a greater awareness of informal caregivers. This awareness stretches across different sectors, from labor laws to healthcare policies right through to the general population. I think that there is perhaps a stronger legal framework for informal caregivers in the United Kingdom.

**SW:** Does the United Kingdom provide economic benefits to informal caregivers?

**EH:** They do. The United Kingdom recognizes caregiver rights. Local councils in the United Kingdom are obliged to perform a caregiving assessment. The compliance is lower in some areas, where the councils lack resources. A caregiving assessment involves a staff member exploring with the carer her or his personal caring situation, through a discussion they identify areas where she or he needs help and together they agree on the type of support that is suitable.

Caregivers have the right to request flexible leave if they are working. This legislation has developed over the years. However, it is important to remember that the welfare system is much weaker in the United Kingdom. There is not the same safety net available.

The Swedish welfare state is smaller today than in the 1970s. Hospitals and care homes have reduced the number of beds. This means that a lot of care happens at home. Despite these cuts, it can be argued that compared to other European Union Member States, caregivers in Sweden tend to obtain adequate support when they care for a person with a disability. Other countries look to Sweden and our disability support. However, I am aware that more recently the assessment process for the allocation of personal assistance has become much more strict with negative consequences for affected caregivers and family members.

There are pluses and minuses with every system. There is generally a lower awareness of informal caregivers in Sweden. I mean in society in general and also healthcare professionals often lack an understanding of informal caregivers. Many people believe that the state is responsible for the delivery of care. Many oversee the role of informal caregivers.

**SW:** What are the greatest opportunities for the future?

**EH:** In my view, and this is from my perspective, the greatest opportunity is the power of the human capacity. Human beings want to care for one another. The family and wider community have a great potential to support individuals. If the modern family changes dramatically, we may see new forms of informal care emerging. We need to be creative. We need to think outside the box.

Researchers need to work with people from all walks of life. As well as working directly with caregivers and the formal health and social care sector, we also need to work with policy makers, business leaders and the voluntary sector. We need to harness new technologies to optimize our human resources. Technology can help us phase out the tasks that we dislike doing.

**SW:** What type of technologies?

**EH:** We need assistive technologies at home, such as bathroom robots. This may allow individuals to shower and carry out toileting needs independently. Robots can help with certain tasks. They do not replace the important human contact. I am not alone in liking the idea of sensor technology and other smart devices at home. They are not intrusive. The future of caregiving will surely include a range of technologies.

**SW:** Thank you very much Elizabeth. This topic is fascinating.

**EH:** Thank you Sofia!

END

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<sup>1</sup> Anhörigvårdares hälsa. Kunskapsöversikt 2010:3. Nationellt kompetenscentrum Anhöriga (NKA). Link [Here](#)

<sup>2</sup> Figure 3. Erlingsson C. et al. (2011). *Family Caregivers' Health in Connection With Providing Care*

<sup>3</sup> Nationellt kompetenscentrum anhöriga, Link [Here](#)

<sup>4</sup> Anhörigvårdares hälsa. Kunskapsöversikt 2010:3. Nationellt kompetenscentrum Anhöriga (NKA). Link [Here](#)

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- 5 Deltidsanställd
- 6 Definition Link [Here](#)
- 7 Socialtjänstlagen Link [Here](#)
- 8 Eurocarers Link [Here](#)
- 9 Lag (2008:962) om valfrihetssystem Link [Here](#)
- [10 Telecare, telehealth, telemedicine: what is the difference?](#)