



Am I a Carer?

First-Hand Guide to Informal Care



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To the reader

The purpose of this guide is to provide first-hand information to you as you care for your loved one. The guide helps you to examine how your life has changed after a loved one has fallen ill or become disabled or after your child has been diagnosed with a chronic disease or disability. As a relative, you help your loved one to cope with everyday activities, provide mental support and learn how to manage in what may sometimes be a complex jungle of services. Perhaps you are wondering how to combine work and caring for your loved one. Are you a carer?

At first, the term 'carer' may seem strange. To your disabled or chronically ill child, you are first and foremost a mother or father. As a spouse, you believe that mutual support and care are a natural part of a life together. Your ageing parents' need for help has increased almost unnoticeably. You have responded to each situation, until one day you notice that your days are filled with supporting or helping another person. Sometimes you realize that you are a carer only after years of providing care.

The first and second chapter describe the informal care situation, its early signs and the various ways in which an informal care relationship may begin. If you notice that you are in an informal care situation, you can consider whether your resources are adequate and whether you need support.

The third chapter examines how and from where a carer can seek necessary information. The fourth chapter describes the services and forms of support provided by society. The fifth chapter emphasises the importance of carers looking after themselves.

The sixth chapter presents the activities of The Central Association of Carers in Finland, and the seventh chapter describes The Finnish Network for Organisations Supporting Family Caring.

We hope that this small guide will provide new perspectives to your current life situation.

Please note that the written materials referred to here are available only in Finnish.

The Editorial Staff

Contents



To the reader	3
1. The Many Faces of Informal Care	6
What does informal care mean?	6
Who is a carer?.....	6
2. Informal Care Begins With a Change	8
Sudden start.....	9
Slow start	9
Identifying informal care situations is important.....	10
Are you a carer?	11
3. Information Helps.....	12
Keys to information	13
4. A Puzzle of Services.....	14
What services and from where?.....	14
Support for informal care	17
The ABCs of collaborating with professional staff.....	18
The future of informal care	19



Photos: Rodeo

5. Look After Yourself	20
Balanced needs	20
Peer support provides strength	21
Combining work and informal care	21
Short-term care places and daytime activities	21
Prepare for difficult moments	22
Strength in everyday life	23
Keys to wellbeing	24
Ovet carer training	24
A holiday helps you to cope	25
Kela's rehabilitation courses for carers	27
6. The Central Association of Carers in Finland	28
Active local associations	29
Become a member	29
7. The Finnish Network for Organisations Supporting Family Caring	31

1. The Many Faces of Informal Care



What does informal care mean?

The need for informal care may emerge in different families in many different stages of life when a loved one falls ill or becomes disabled or when a disabled or chronically ill child is born into the family. Informal care is often based on a relationship that has already existed before informal care begins.

Informal care is a situation in life when an illness and a disability, help and support are integrated into the ordinary life of the family in various ways. In an informal care situation, both the carer and the care receiver need support.

Who is a carer?

Over one million Finns help their relative or loved one in some way, and about 350 000 of them are so-called primary caregivers to their loved one and about 60 000 are in a binding and demanding informal care situation. In 2013, roughly 42 500 carers received support for informal care granted by the municipality pursuant to the Act on Support for Informal Care.

According to the Act on Support for Informal Care, "a carer is a relative or another person who is close to the care receiver who has signed an informal care agreement with the municipality".

This guide applies the definition of a carer given by The Finnish Network for Organisations Supporting Family Caring.

A carer is a person who takes care of his/her family member or other loved one who cannot cope independently with everyday activities due to an illness, disability or other special need for care. (*The Finnish Network for Organisations Supporting Family Caring*)

Thus, the majority of caregivers provide support for their relative without help from the society. When a relative recognises that he/she is in an informal care situation, he/she can obtain information and guidance as well as support at home more easily.

A carer can be the spouse, father or mother, sister or brother, child, other relative, friend or neighbour of the person in need of help. Some help their loved one daily in many different ways, while others only help in certain activities or occasionally.

Not all carers provide physical help: they do not dress, wash or feed the person. The need for help is not always obvious. If one family member suffers from e.g. problems in brain activity or mental health, the relatives are left with many kinds of guiding and supervising tasks.

"He was no longer interested in our finances, although he used to handle them before." (wife)

"He didn't feel like talking about anything anymore." (daughter)

"Her identity has gradually disappeared and that obviously affects our relationship." (husband)

Many help their loved one from another locality, i.e. they are so-called remote carers. Remote carers may care for their loved one also by phone and remote technology.

"It was difficult to notice that now my mother needed me more than I needed her." (son)

"I visit my father-in-law every Saturday, go shopping for him, clean and run errands. In the evening, my children wonder why I'm so exhausted." (daughter-in-law)

2. Informal Care Begins With a Change



When a loved one falls ill or becomes disabled, the family member repeatedly finds him/herself in a situation where help must be provided. The desire to help may stem from love, affection or a sense of duty.

The change touches each family member. Relatives and friends must find a new balance of interacting in everyday encounters. The internal relations of the family and the initial situation of informal care affect the care relationship. If the relative feels a strong sense of duty or pressure from the environment at the early stage, the impact of being a carer on his/her own life and strength may be difficult to assess.

“My head somehow refused to take it in. It took perhaps several weeks before I realized that now I have to rebuild my life altogether.” (husband)

There is not always time to hear the relative during brief hospitalisation periods. Due to this, his/her willingness and readiness to become a carer may remain unclear. Social and healthcare professionals should provide support during the transition. As the carer of your relative, you may also broach the topic yourself and inform the professional staff of your personal thoughts, needs and wishes.

“It was great to meet nurses who understood that once that guy gets over the shock, he faces a new situation in life.” (husband)

Tasks and responsibilities within the family have to be reassigned when a family member's ability to function changes. Integrating other tasks into care-related tasks requires planning

as well as finding essential help and services; you do not have to manage on your own.

“I haven’t received much advice, I’ve learnt how to use the washing machine and dishwasher by myself.” (elderly husband)

“We had to move, because of these horrible stairs. We had to make those decisions alone.” (wife)

“Everyday life requires a lot of organising; I go shopping and run errands while he’s taking a nap.” (co-habiting spouse)

Informal care involves new tasks, such as guidance and supervision, treatment, personal assistance, the use of assistive devices and cooperation with various professionals.

“Nowadays I feel like I’m more of a nurse than my wife is.”

The birth of a disabled child or the chronic illness of a child poses new challenges to parenthood. Parents must decide on how to integrate the needs of a disabled or sick child into the course of daily life. In this case, the challenge is to also take the other children in the family into consideration and support them.

“Life involves constant monitoring of the child’s condition and acting accordingly.” (parents)

“My husband and I try to spend one-on-one time together on a regular basis.” (mother)

Sudden start

When a loved one suddenly falls ill or becomes disabled, the change is devastating. The need for informal care emerges suddenly in the case of e.g. accidents, strokes or the birth of a disabled or chronically ill child. The feelings of the entire family and their relatives are in turmoil. The biggest concern may be whether their loved one will live.

“It was such a shock that one can’t even ask questions at that stage.” (daughter)

“I sort of realized that something serious had happened, but here we are, fighting and seeing how far we can go.” (wife)

Slow start

The change in the ability to function due to a progressive illness becomes slowly apparent. The family member gradually begins to need more and more attention or help. Changes are adapted to, and the precise start of informal care is difficult to determine. The first changes may occur inconspicuously in everyday life and emotions. If a family member falls mentally ill, the altered behaviour of the person may not immediately be identified as an illness.

“Informal care began when I had to carefully consider how my father will cope while I’m gone every time I left home.” (son)



Identifying informal care situations is important

Social and healthcare professionals are the key to identifying informal care situations. Many carers have expressed a hope that professional staff would actively and spontaneously invite the carer to cooperate and provide guidance and advice. If the staff have not discussed a potential informal care situation, the relative may broach the topic him/herself.

“The doctor said at the very beginning that I’m a doctor, they’re nurses and you’re part of the team, let’s do this together. That was our starting point and perhaps that has been one of the reasons why I’ve managed as well as I have.” (daughter)

“When they only ask the patient... They should also interview the wife about how he is and what he can do.” (spouse)

Mikkeli Association created a video and a test online

The Association of Family Carers and Relatives in the Mikkeli Region has created the website www.tunnistaomaishoitaja.fi. The site has a video entitled “Mitä jos asettuist hetkeksi toisen asemaan” (“Why not put yourself in someone else’s position for a while”) and a “Tunnista” (“Identify”) test that can be filled in electronically and used to examine your own potential informal care situation.

Are you a carer?

Assessing your own situation is not always easy. Identifying whether someone is an informal carer can be difficult even for professionals. The following questions may help you to consider whether you are a carer.

The situation of your relative

- Has your relative fallen ill or become disabled?
- Has the personality of your relative changed?

Coping with everyday activities

- Do you help your relative with everyday activities?
- Has the distribution of responsibilities in the family changed?
- Has your workload at home increased?
- Do you often worry about your relative or your situation in life?

Need for services and assistance

- Has the need for social and healthcare appointments and visits to offices increased?
- Do you need a substitute carer for your relative when you are absent?
- Have you had to make room for assistive devices and care supplies at home?

Personal wellbeing

- Do you have less free time?
- Do you sleep less at night?
- Has your own health deteriorated?
- Are your personal needs and desires put aside?
- Has your circle of friends narrowed?
- Have you noticed that the things mentioned above burden you?

If your answer to multiple questions was 'yes', your family may be in an informal care situation that is just starting or has already started. Consider how much responsibility for care you can take. What do you have the strength for? What kind of information and support do you need? Are you aware of support for informal care? Contact healthcare and social workers, the social services of your own municipality, home care or the nearest local association of The Central Association of Carers in Finland.

Association's photography exhibition about informal care families

"Likellä – tarinoita omaishoidosta" ("Nearby – Stories about Informal Care"), a photography exhibition by Lakeuden Omaishoitajat ry, tells the story of four different informal care families. The photographer is Riikka Austen. The exhibition can be viewed until the end of 2016 at www.likella.fi

3. Information Helps



A family member has the legal right to obtain information from healthcare services about the illness, treatment and rehabilitation of a relative with the consent of the relative.

Public health, disabled and mental health associations; Kela; insurance companies and municipalities provide various service guides. They contain information about illnesses, rehabilitation, benefits and services that support informal care and how to apply for them.

The service guide of The Central Association of Carers in Finland contains information particularly for carers and instructions on how to apply for services. The service guide is available (in Finnish) on the website of the association at www.omaishoitajat.fi.

“My head certainly doesn’t take everything in. Things really need to be written down on paper.” (mother)

The informal care helpline is available at the number 020 7806 599 (Mon. – Thu. 9 am – 3 pm). The helpline is subject to a charge.

Information is also available from adaptation training courses and rehabilitation courses organised by Kela, the Ovet carer training sessions organised by the association’s local associations in cooperation with local agents, first-hand information days, the members’ magazines of associations and other carers.

If you are not used to dealing with officials, first contact a social worker or case manager

at your municipality, hospital or health centre. If the official cannot help you, you will be referred elsewhere.

“Nowadays I push my way into the doctor’s office and everywhere so that I’d know about the essential things. This man can’t say anything to the doctor, so the whole appointment would be useless. I have to know, if I’m the one who’s responsible.” (wife)



The materials of The Central Association of Carers in Finland contain important information for carers (in Finnish).

Keys to information

- Ask a doctor, a nurse or various therapists about the illness, treatment and rehabilitation of your relative and how the condition affects coping with everyday activities.
- Also ask about the right way to help, assistive devices and social security.
- Ask the professional staff to explain things multiple times so that you understand them clearly.
- If necessary, request a one-on-one meeting with the professionals.
- Also request written instructions and notices.
- Ask about the first-hand information days and adaptation training courses.
- Obtain information about maintaining your own health and ability to function.
- Find out about patient and disabled associations related to your relative’s illness or disability and follow their notices and websites.
- Find out about the peer support groups for carers in your region.
- Be active and don’t back down!

4. A Puzzle of Services



The social and healthcare service system provides diverse forms of support for a carer. Personal initiative and active enquiries help in the search for services. Services need to be applied for; they are not provided automatically. The service package is planned in cooperation with the family and the officials.

If the decision received by the family is unclear, unlawful or feels unjust, rectification may be demanded. The instructions are attached to the written decision. Advice may be requested from the Social Welfare Ombudsman in issues concerning social service decisions and the Patient Ombudsman in issues concerning healthcare decisions.

What services and from where?

MUNICIPALITIES

- **support for informal care:** services to the care receiver, care allowance to the carer, leaves and support for the carer, cf. page 17 of the guide for more details
- **home care:** domestic services and home nursing, support services for home care, e.g. catering, bathing, laundry and shopping services as well as safety phone services the running of errands
- **short-term care and daytime activities for the care receiver**
- **services for the severely disabled:** housing services, apartment modifications, transport and accompanying services, personal assistance, daytime activities
- **discretionary services:** special meals and clothing; financial support for devices, machines

(e.g. a car) and equipment; rehabilitation; adaptation training

- **supported living**

Additionally for families with children

- child health clinic, day-care, parenting guidance and family counselling, child welfare
- day-care and school helpers, remedial and special instruction

Primary health care (health centre)

- healthcare and medical care, examinations
- rehabilitation; individual, group and veterans
- assistive devices that support daily activities, alarms and access control systems
- care supplies
- mental health services

Special health care

- special health care procedures, examinations, nursing, social work, medical rehabilitation and rehabilitation guidance
- special assistive devices for mobility, sensory processes and communication that support daily activities
- mental health services (outpatient clinic, institutional), rehabilitation guidance

Municipalities



KELA

- rehabilitation (professional, discretionary and that of a severely disabled under 65-year-old) and adaptation training for the care receiver and carer
- disability benefits, disability allowance for children under 16 or persons aged 16 years or over and care allowance for pensioners
- special care allowance for caring for a sick or disabled child
- sickness allowance
- medicine reimbursements; reimbursements of the costs of private medical care, dental care and rehabilitation and the related travel allowance
- assistive devices for studying

www.kela.fi

THE CENTRAL ASSOCIATION OF CARERS IN FINLAND

- guidance and advice, helpline tel. 020 7806 599, subject to a charge
- information and training
- social influence and development
- leaves for carers and rehabilitation
- "Lähellä" magazine, books and other publications

LOCAL ASSOCIATIONS

- guidance and advice
- information
- excursions and events
- peer support groups
- holidays and recreation
- social influence
- Ovet carer training

www.omaishoitajat.fi

OTHER ORGANISATIONS AND ASSOCIATIONS

- many associations for relatives in addition to public health and disabled associations provide services that support informal care families
- mental health rehabilitees have their own association, the National Family Association Promoting Mental Health in Finland – FinFami with regional associations
- also e.g. the Finnish Red Cross organises activities and training for carers
- Folkhälsans förbund organizes activities for carers and disseminates information in Swedish

PARISHES

- groups, recreational days, lectures, camps
- welfare work, spiritual support and confidential conversational therapy

INSURANCE COMPANIES

- compensations and financial support for occupational and traffic accident patients

- rehabilitation, treatment, assistive devices, compensations

PRIVATE SERVICE PROVIDERS

- substitutes for carers on leave, domestic aid services
- cleaning
- daytime activities
- nursing homes

OTHER SERVICES

- police department: disabled parking
- customs district, Hanko: vehicle tax deduction
- tax office: household and disability deduction and deduction for reduced tax-paying ability
- family care

Support for informal care

Support for informal care refers to an entity that takes into consideration both the care receiver's and the carer's need for support and services. Support is applied for from the care receiver's municipality of residence. More information is available from the social services office of the municipality. Support cases are usually handled by the (domestic services) case manager or a social worker for the elderly or the disabled. The official responsible for the support will make a home visit once the application has arrived.

Support for informal care is not a so-called subjective or absolute right, but the municipality reserves an annual allocation for it. The Act on Support for Informal Care defines the prerequisites for granting support and the minimum care allowance. Municipalities determine their own, more detailed criteria and care allowance classes based on these. The criteria for granting support, their assessment methods and the amount of care allowance therefore vary from one municipality to another.

The majority of carers work without support for informal care. For instance, the relatives of mental health rehabilitees have rarely received a favourable decision concerning support for informal care, although they have to monitor the condition of their loved one on a daily basis and help him/her seek treatment. If the conditions for a support for informal care agreement are not met, many other forms of support services are still available for homes. It is important to find out what practical help the municipality, private service providers or associations provide in your locality.

Support for informal care includes

- services provided to the care receiver
- care allowance granted to the carer
- carer's leave: 3 days during each month that the carer has been bound to provide around-the-clock care or constant daily care
- other services that support informal care

One is eligible for support for informal care if

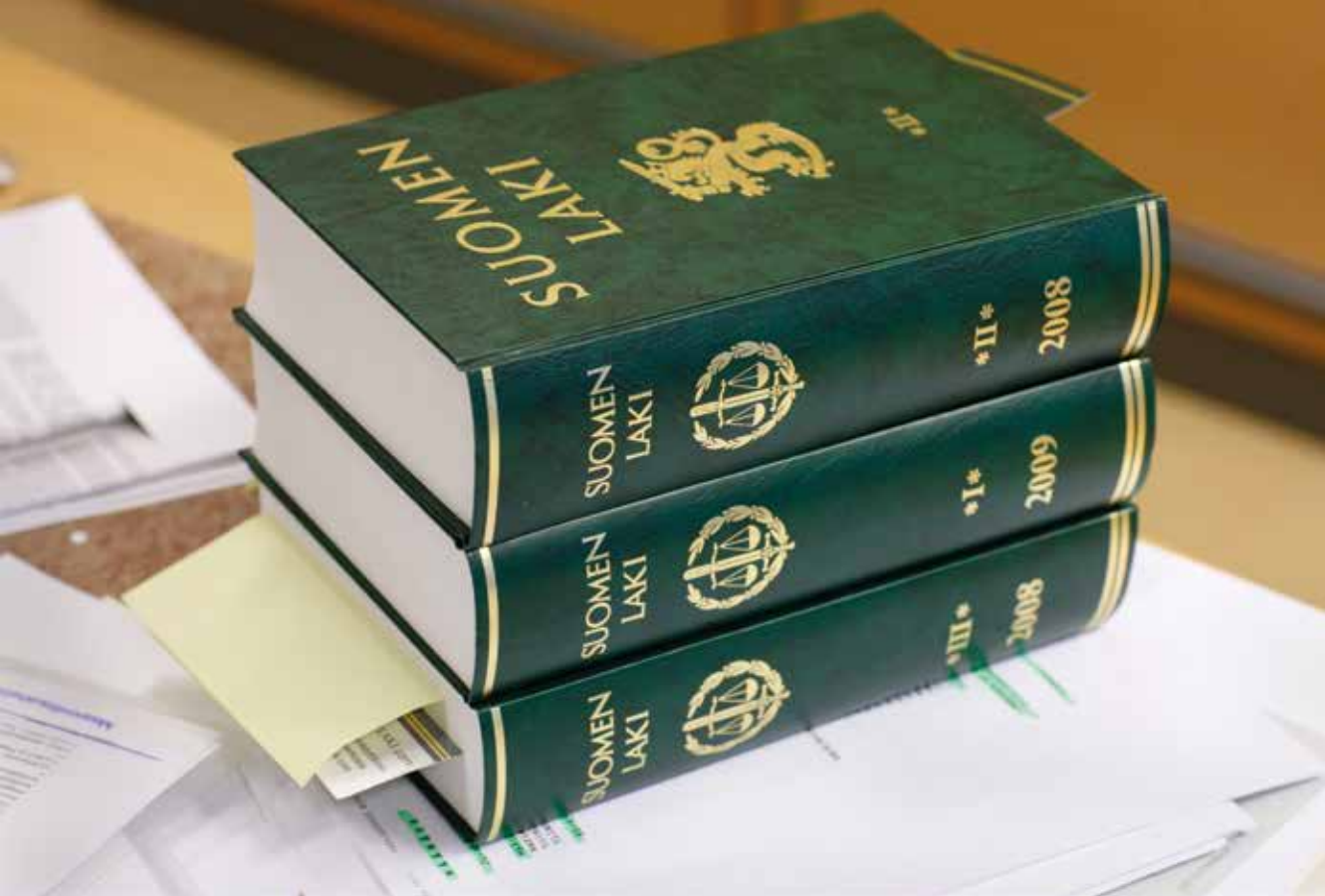
- the care work is binding and demanding
- one is ready to take responsibility for care and nurture with the help of other services
- one's health meets the requirements for providing informal care
- the care receiver's home is suitable for the care provided in it
- informal care together with other services is sufficient for the wellbeing, health and safety of the care receiver
- granting support is judged to be in the best interests of the care receiver

Other important matters

- An agreement concerning support for informal care is established between the carer and the municipality and includes a written care and service plan.
- As a rule, care allowance accumulates pension.
- The municipality that has made an agreement with a carer is obligated to provide accident insurance for the carer that covers informal care situations.
- The municipality must organise substitute care for the care receiver during the carer's leaves.

The ABCs of collaborating with professional staff

- Do not hesitate to bring up issues that cause you concern.
- Discuss the needs and wishes of your relative if he/she is not able to do so.
- Say if you notice anything different in the behaviour or condition of your relative.
- Describe how and with what you help your relative and what kinds of situations at home you would need more help with.
- In the hospital, ask to be involved in planning the discharge. Request for a home visit, if necessary.
- Describe your health restrictions and personal needs and wishes.
- Assess your personal resources honestly and describe your ability to cope.
- Request that the care and service plan also outlines the carer's needs. The helper and the receiver of help may have different opinions on the need for help.
- Jot down your comments and questions in advance and take the paper with you when you visit e.g. the doctor with your relative.
- You may want to keep a diary about your relative's need for help.
- Save all the medical statements, prescriptions, decisions and other papers concerning care and rehabilitation in a folder where you can easily find them if you need to.
- Place important phone numbers somewhere visible. This is useful when communicating with professionals.
- Remember that as a carer, you are a social and healthcare customer who has certain rights.



The future of informal care

A proposal for the first national development programme for informal care (KOHO) was issued in 2014 by a broad-based team. The programme includes e.g. a goal to enact a new Act on the Support for Informal Care. Therefore, the informal care support system may undergo changes in the upcoming years. Follow the website of The Central Association of Carers in Finland at www.omaishoitajat.fi and the media.

The national development programme for informal care is available in Finnish at: <http://www.julkari.fi/handle/10024/116146>.

The permanent link to the publication is: <http://urn.fi/URN:ISBN:978-952-00-3483-2>

5. Look After Yourself



Balanced needs

Many informal carers say that they feel good themselves when their loved one feels good and stable. Being a carer is rewarding. It also takes a toll on the carer's mental and physical strength. The future may seem daunting. Questions and uncertainties may fill one's mind. The carer must find a balance between his/her own life and informal care tasks.

It is important that the family members of informal care families lead a full, age-appropriate life and engage in hobbies and enjoy life as much as possible. By enhancing and holding onto the strong aspects of life, one can try to find a balance in life.

If life is unbalanced, there is a risk of one of two extremities. Undercaring means that the carer does not take the care receiver's needs into consideration. In this case, the care receiver's wellbeing is at risk. Overcaring means that the carer does not recognise or take his/her own needs into consideration. In this case, personal wellbeing and the ability to cope are at risk. Maintaining a good balance is vital right from the start of an informal care situation.

“The nurse reminded me to look after myself, but there was no way to see what was coming in that situation.”

Friends, relatives and loved ones are happy to help. They should be informed of the family's situation and needs. In this way, the carer can allow them to help. Associations and parishes have voluntary support persons and helpers. Do not hesitate to ask!

Peer support provides strength

Peer support is the sharing of experiences with others in the same situation. In a peer support groups for carers, you can listen to others, be heard and seek solutions for common problems. You may find new perspectives, learn from each other and receive mental support.

Many municipalities have a local association under The Central Association of Carers in Finland and/or an association for relatives under the National Family Association Promoting Mental Health in Finland – FinFami. Everyone who is interested in informal care or is caring for their loved one is welcome to take part in the activities regardless of whether they receive support for informal care or not. Also, participation does not require association membership.

Associations organise training days, group activities, excursions and other recreational events for carers. Many public health and disabled associations also provide information and activities to relatives. Peer support groups are also organised by parishes and some municipalities. Folkhälsans förbund organizes group activities for carers in Swedish on different locations.

“The peer support group said that if you run out of strength, you’ll find yourself in a pickle, trying to figure out how to organise your life.” (son)

Combining work and informal care

A large number of carers also go to work. Many wonder how to divide their strength and time between work, family life and care as well as their personal life. It is a good idea to discuss the arrangements for combining work and informal care with the employer, occupational health care and/or a social worker.

According to the Employment Contracts Act (Chapter 4, Section 7), employees are entitled to temporary absence from work if their immediate presence is necessary because of an unforeseeable and compelling reason (due to an illness or accident) suffered by their family. Absence for taking care of a family member or someone close to the employee was added to the Employment Contracts Act in 2011. The employee agrees on the conditions of absence with the employer. Various kinds of flexible work and working hours arrangements, job alternation leave, remote work, a working time bank, a part-time pension, a part-time supplement or partial child-care leave may also be possible.

Short-term care places and daytime activities

Temporary care places are essential for the coping of the carer. It is a good idea to become familiar with them in advance. Many municipalities also organise daytime activities during which the carer may run errands and take time for him/herself.

Short-term care places are available in health centres, retirement homes, sheltered accommodation and private nursing homes. You should inform the domestic services case manager, the SAS nurse (= the municipal or hospital employee who serves as the contact

person between home and other forms of housing) or a home care worker of the need for a care place as early as possible.

“I’m the one who chose this interval thing. It’s been alright in my opinion. It means that I get to sleep or do my own work in peace for one week.” (wife)

Prepare for difficult moments

Day-to-day informal care involves feelings of love, hate, guilt, fear, gratitude, joy, sorrow and a sense of duty. Sometimes anger is a useful feeling that gives you the strength to say: this is where I draw the line, I can’t take it anymore!

It is not always easy to identify, accept or express your feelings. Unexpressed feelings may form an obscure burden that makes everyday life difficult. Negative feelings should be expressed as well.

If expressing or discussing your feelings feels difficult in light of the situation at home, you should consider ways to process your feelings that suit you. Would writing or listening to music help, or do you have friends or other carers whom you can share your feelings with? A carer needs free time and holidays, especially when the informal care situation is long-term and binding.

*Just one day and one moment at a time.
When one has to act on behalf of
someone else, one hardly remembers oneself.
Sometimes one sends that person regards.*

Original Finnish by Helena Anhava

A carer has a high risk of burnout. Long-term excessive tiredness predisposes the carer to burnout and depression. Persistent melancholy that continues from one week or month to the next, sleeping disorders, changes in appetite, irritability, tearfulness, irrational feelings of guilt and a lack of joy in life are signs of burnout or depression. Efficient, expert care is available even for severe depression.

“I always wake up in the early hours of the morning and can’t get back to sleep.” (sister)

“At some point you experience a kind of – exhaustion that is so treacherous.” (husband)

“What will happen to him if I fall ill as well?” (single mother)

No matter how much you want to, you cannot always help in the way that you wish. Admitting and tolerating your own powerlessness reduces the feelings of guilt and failure. The time may come when your loved one moves to a care facility outside the home temporarily or permanently.



It is entirely natural that it may feel difficult at first to allow others to take care of a loved one or, for instance, to see a disabled young person move away from home or become independent. The feelings on both sides may delay the making of these necessary decisions. Short-term care periods help both the carer and the care receiver anticipate a situation where the care receiver may move permanently to a care facility or supported housing away from home.

Strength in everyday life

Recharging the battery is a good metaphor for replenishing your strength. When you recover your strength on a daily basis, your wellbeing improves, your tolerance increases and you perform your duties better. An ageing carer needs more time to recuperate than a young one. It is a good idea to practice how to arrange resting periods from the start and learn to trust that the care receiver is safe even when the carer is not present. Arranging extended leaves requires planning. Disengaging oneself from care work does not mean forgetting or neglecting the other person. In addition to rest, recovery is facilitated by sleep, relaxation, pleasant hobbies and social contacts.

Physical exercise also has positive effects on health and wellbeing. It is important to find a form of exercise that you enjoy. Even a few times a week and brief outdoor activities on a daily basis improve your general condition. Exercise helps to recover from stress and renews your strength.

Smooth everyday routines; meeting friends, neighbours and relatives as well as own hobbies help to maintain a balance in a carer's life. You can gain strength from e.g. writing, exercise, listening to music, reading, painting, crafts, acting, going to concerts, walking in the forest, baking or talking to others.

Keys to wellbeing

- Listen out for signs that reveal how you are coping and take them seriously.
- Reserve enough time for rest and recreation.
- Exercise outdoors on a daily basis.
- Enable something enjoyable for yourself every day.
- Arrange shared moments of joy with your family and the care receiver. Enjoy them!
- Think about the sources of strength in your own life and cherish them.
- Consider your own values: what is important to you and brings you satisfaction.
- Go and meet other carers in a peer support group.
- Do not be left alone.
- Remember that you are an important person to yourself!

Ovet carer training

Ovet is a 16-hour training programme developed by The Central Association of Carers in Finland to support those caring for their loved one. The training focuses on embracing carers' personal strengths and finding new resources together with other carers. Folkhälsans förbund has translated Ovet concept in Swedish and the courses are called Öppna dörrar.

Ovet carer training supports informal care and makes it easier for carers to proceed along the informal care path. Everyone who is helping a loved one in need of help is welcome to take part in training. The free training consists of group activities on issues related to informal care, accompanied by introductions, discussions and exercises.

Key themes concern the signs of an informal care situation, the services provided by society, the basics of helping and nursing and change as a part of life. Training is also available via an online application that is open twice a year (only in Finnish).

The local associations of The Central Association of Carers in Finland provide training in cooperation with local partners around Finland. Folkhälsans förbund with other actors organize Öppna dörrar courses in Swedish. Information about the training sessions provided in your own region is available on the association's website at www.omaishoitajat.fi or from local associations and www.folkhalsan.fi/narstaende.



A holiday helps you to cope

The Central Association of Carers in Finland arranges about 20 carer holidays each year in cooperation with Maaseudun Terveys- ja Lomahuolto ry, Solaris-lomat ry and Hyvinvointilomat ry. These so-called social holiday organisations arrange subsidised holidays with support from Finland's Slot Machine Association (RAY). Folkhälsans förbund organizes holidays in Swedish in cooperation with Svenska semesterförbundet. The holiday organisation grants holidaymakers a holiday subsidy, which covers the majority of the price of the holiday. The holidaymaker pays the excess and the journeys.

Subsidised holidays for informal carers bring together carers who are in a similar situation or have common interests. Some of the holidays are for both the carer and the care receiver.

Holidays are usually five days long. They are half-board or full-board. Accommodation is provided in double rooms. The agenda of a carer holiday consists of activities related to informal care, activities ordered by the holiday organisation and general recreational activities at the destination. A holiday instructor from the association takes part in carer holidays and organises the group's daily meetings and the activities related to informal care.

Order the application form of a holiday organisation by phone or print it from the website

From The Central Association of Carers in Finland

Holidays and rehabilitation courses 020 7806 533 or www.omaishoitajat.fi.

From holiday organisations

Maaseudun Terveys- ja Lomahuolto ry
tel. 010 219 3467
www.mtlh.fi

Solaris-lomat ry
tel. 0600 418 200
www.solaris-lomat.fi

Hyvinvointilomat ry
tel. 010 830 3400
<http://hyvinvointilomat.fi>



Fill in the form carefully. You do not need to attach any medical statements or records of income. Return the application form to the holiday organisation providing the holiday.

Kela's rehabilitation courses for carers

Kela organises rehabilitation courses for carers as both individual and pair courses. The carer and the care receiver both take part in pair courses.

Rehabilitation courses for carers are for people who act as informal carers on a daily basis and need rehabilitation due to an illness and/or possible symptoms of burnout. Participation is granted on the condition that the carer's ability to function can be ensured or improved with the rehabilitation in question. Carers may be of different ages, and receiving support for informal care is not a prerequisite for participation.

The period in the rehabilitation centre is free of charge to the rehabilitee. Substitute care during rehabilitation may incur expenses to the informal care family. Periods in a rehabilitation centre during pair courses are free of charge to both the rehabilitee and the relative receiving care.

More information on rehabilitation courses is available on Kela's website at www.kela.fi and from the offices by phone as well as from The Central Association of Carers in Finland, tel. 020 7806 533.

6. The Central Association of Carers in Finland



There are only four kinds of people in this world

*Those who have been caregivers;
Those who currently are caregivers.
Those who will be caregivers; and
Those who will need caregivers.*

Rosalynn Carter

Are you a carer?

The Central Association of Carers in Finland (Omaishoitajat ja läheiset -liitto ry, Förbundet närståendevårdare och vänner rf) is a support and advocacy association for carers and persons receiving care. The association was founded in 1991. It has 69 local associations and more than 11 000 individual members (June 2015).

The association strives to improve the social status of carers on a national level by e.g. giving comments and statements and influencing legislation and the public opinion. The association provides guidance and advice as well as training on issues related to informal care. Various development projects are carried out to support informal care families.

Informal care helpline Mon. – Thu. 9 am – 3 pm, tel. 020 7806 599
The helpline is subject to a charge.



Hämeentie 105 A 18
00550 Helsinki
Tel. 020 7806 500
www.omaishoitajat.fi



Follow us on Facebook: www.facebook.com/omaishoitajatjalaeiset

Active local associations

Local associations provide advice and information to carers and allow them to meet others living in the same situation. The associations organise various peer groups, excursions, events, training and recreation for carers. In addition, they supervise the interests of carers on a regional scale, provide opportunities for voluntary work and a forum for making a difference in society. Some associations have projects for immigrant carers.

Become a member

As a member, you will receive the quarterly "Lähellä" magazine, the service guide, the holiday and rehabilitation course guide for carers, membership in a local association and changing benefits from cooperation partners. You can also become a member online at www.omaishoitajat.fi. The membership fee is €20 per year (in 2015).

If you already know which local association you wish to join, write the name of the association on the joining form; otherwise you will be made a member of the local association closest to you.



The Central
Association of
Carers in Finland

I wish to become a member
of a local association of The Central
Association of Carers in Finland.

FILL IN PRINT LETTERS

Name of the local association:

Surname:

First and middle names:

Address:

Postal code: City:

Join online at
www.omaishoitajat.fi



Vastaanottaja
maksaa
postimaksun

Omaishoitajat ja läheiset -liitto ry
Förbundet närståendevårdare och vänner rf

TUNNUS 5009275

00003 VASTAUSLÄHETYS

7. The Finnish Network for Organisations Supporting Family Caring

The Finnish Network for Organisations Supporting Family Caring (Suomen omaishoidon verkosto) is a body of national organisations, foundations, communities and research institutions working in the field of informal care or in a field closely related to this.

According to its mission, the network promotes the development of informal care and cooperation between different actors and strives to improve the status of informal care families in various ways. The network operates on both a national and a regional level. It is a member of Eurocarers – European Association Working for Carers, and also conveys know-how developed in other countries to support carers in Finland.

The network organisations have an extensive network of members that covers a large number of Finns. Joint comments and statements allow the network organisations to work on behalf of informal care more efficiently than individual associations on their own.

Regional teams operative independently based on the local needs of informal care. The teams organise e.g. recreational days, training sessions and seminars for carers. Some of the teams provide training and peer support for the employees and volunteers of associations.

In terms of its administration, the network operates under commission from The Central Association of Carers in Finland. Practical tasks are handled by a coordinator together with a working committee composed of representatives of member associations.



The Finnish Network for
Organisations Supporting
Family Caring

The Finnish Network for Organisations Supporting Family Caring has 12 member associations in 2015

The Finnish Brain Association, www.aivoliitto.fi

Folkhälsan Association, www.folkhalsan.fi

The Service Foundation for People with an Intellectual Disability, www.kvps.fi

Inclusion Finland KVTL, www.kvtl.fi

The National Family Association Promoting Mental Health in Finland – FinFami ry, www.finfami.fi

The Alzheimer Society of Finland, www.muistiliitto.fi

The Finnish Kidney and Liver Association, www.musili.fi

Omaisena edelleen Association, www.omaishoidonverkosto.fi

The Central Association of Carers in Finland, www.omaishoitajat.fi

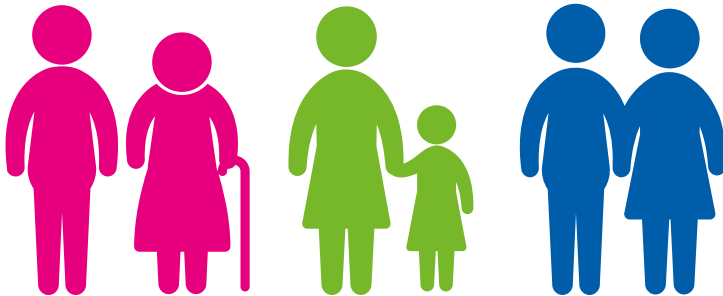
The Finnish Parkinson Association, www.parkinson.fi

The Finnish Red Cross, www.punainenristi.fi

Valli – The Finnish Union for Senior Services, www.valli.fi

Other organisations working in the field of informal care are also welcome to join.

www.omaishoidonverkosto.fi



Photos: Freepik

Notes



The early stages of informal care

More than one million Finns help their sick or disabled relative or loved one in some way. However, many caregivers have not realized that they are living in an informal care situation. The term 'carer' may seem strange.

The guide entitled '*Am I a Carer?*' has been compiled in cooperation with carers and associations. The purpose of the guide is to encourage the caregiving relative to stop and consider how his/her life has changed after a close person has fallen ill or become disabled or a child has received an unexpected diagnosis.

The guide describes the most common signs of an informal care situation. Relatives can use them to examine the changes in the people close to them in relation to their own life.

Once relatives realize that they are informal carers, it is easier for them to seek information and services that are needed in order to be able to divide their strength better than before.

Lakeuden Omaishoitajat ry
www.lakeudenomaishoitajat.fi

Mikkelin seudun Omaishoitajat ja Läheiset ry
www.mikkelinseudunomaishoitajat.fi

Joensuunseudun Omaishoitajat ja Läheiset ry
www.joensuunseudunomaishoitajat.fi

The Central Association of Carers in Finland
www.omaishoitajat.fi

A carer card protects the care receiver

The purpose of a carer card is to protect the person receiving care in a situation where the carer is unable to care for the person due to e.g. an accident or other unexpected cause.

When the card is found in a carer's wallet, helpers become aware of the care receiver and can contact the people or parties mentioned on the card.

Make sure that the individuals mentioned on the card know that they have been listed as contact persons. In addition, it is a good idea to instruct them on how to behave if you are unavailable and to update these instructions when necessary.

The carer card has been developed as the result of a field trip to Sweden by the City of Helsinki and Pääkaupunkiseudun Omaishoitajat ja Läheiset ry.



I am a carer and responsible for my cared-for person.
If I am unable to care for her/him in case of an accident
or other unexpected cause, please contact the persons
mentioned in the card.

**Omaishoitajat
ja läheiset**
-liitto ry

The Central
Association of
Carers in Finland

Carer card
Omaishoitajakortti

Olen omaishoitaja ja vastuussa henkilöstä, joka on riippuvainen antamastani avusta. Mikäli joudun onnettomuuteen tai en muuten pysty huolehtimaan hoidettavastani, ota yhteyttä kortissa mainittuihin henkilöihin.

<p>My name: Oma nimi:</p>	<p>1st contact person / Tel. / Family or other relationship: 1. yhteyshenkilö / puh. / sukulais- tai muu suhde:</p>
<p>Care receiver's name / Tel. / Family or other relationship: Hoidettavan nimi / puh. / sukulais- tai muu suhde:</p>	<p>2nd contact person / Tel. / Family or other relationship: 2. yhteyshenkilö / puh. / sukulais- tai muu suhde:</p>
<p>Additional information: Huomioitavaa:</p>	<p>If not reached, please call 112. Ei-lei henkilöitä tavoiteta, ota yhteyttä hätänumeroon 112.</p>

Fill in the card and keep it with you at all times

You should always keep the card with you. When you fold it, it takes up no more room than a credit card.

The card is ready to use when you have filled in your own and the care receiver's details and added who or which party should be contacted in the case of an emergency. You can name individual contact persons or direct calls to e.g. the emergency social services, a crisis centre or the emergency number 112.