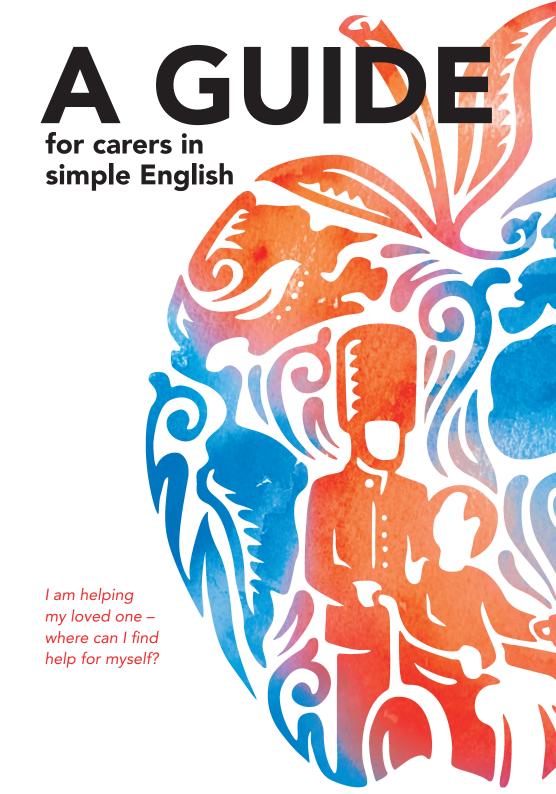


I am helping my loved one – where can I find help for myself?

Pääkaupunkiseudun Omaishoitajat ja Läheiset ry The Association of Carers in Helsinki and Vantaa (POLLI)







Do you take care of a loved one who can't cope in daily life without your help? Are you the carer of your loved one?

This guide provides information in simple English about caregiving and other relevant issues. This guide tells you about what caregiving is and about the support you can apply for it in Finland.

As a carer, you will need information on how the care system works in Finland. You will also need practical advice to help you manage with daily tasks.

People and their basic needs are similar all over the world.
Cultures and customs may differ,
but everyone needs care and attention at some point in their life.

There are many carers in Finland. You are not alone in your situation.

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#### **Contents**

<ul> <li>Introduction</li> </ul>	4
• Are you a carer?	6
<ul><li>What is caregiving?</li></ul>	8
<ul> <li>The stages of caregiving</li> </ul>	11
<ul> <li>Support and services for carers</li> </ul>	14
<ul><li>What is support for informal care?</li></ul>	15
<ul> <li>How do you apply for support for informal care?</li> </ul>	17
<ul><li>What is included in support for informal care?</li></ul>	18
<ul> <li>Other support services for carers</li> </ul>	22
<ul> <li>Social benefits granted by Kela</li> </ul>	24
Work and caregiving	26
<ul><li>Carer – take care of yourself!</li></ul>	27
<ul> <li>Support from other people</li> </ul>	29
Carer associations	32
Other associations	35
• Churches	37

### Introduction

This guide provides information in simple English about caregiving and other relevant issues.
This guide tells you about what caregiving is and about the support you can apply for it in Finland.

People sometimes need help in everyday life, such as in eating and dressing.

The need for help may be caused by, for example, old age, a physical disability or falling ill.

At times like these, a person can't take care of himself and needs help from another person.

Friends and family are most often the most important helpers. If a person continuously needs help from a loved one, they become a carer. This means that the carer will spend their own time and resources on caring for another person.

This guide is for carers.

A carer may be granted financial support to care for their loved one. You need to apply for services and social benefits. This guide tells you where you can apply for them.

As you read this guide, you can think about which service or social benefit would help you and your loved one in this situation.

A carer also needs practical advice on how to cope with everyday activities with a loved one.

#### Read the guide!

Contact the authorities if you are tired or lonely. Tell a social worker or a doctor, for example, about your situation at home and about how you take care of your loved one. If you feel that you do not get help, contact them again.

Things may seem difficult and complicated.
Questions, advice and explanations
will help to clarify the situation.
The authorities' duty is to help you and your loved one.
Ask questions and listen to what the authorities tell you.
Explain your own situation openly and clearly.
If it is difficult for you, you can tell them that as well.
The authorities are always bound by confidentiality.
This means that they are not allowed to tell anyone else about you and your family.

Take a support person with you if it is difficult for you to work with authorities because of a language barrier, for example. You can request for an interpreter if you can't speak Finnish well enough.

People are the same everywhere, even though cultures and customs are different. Everyone worries about the health and wellbeing of their loved ones. Everyone understands that.

You don't have to be alone with your worries.

# Are you a carer?

Many people may be carers without knowing it themselves. With the following questions, think about whether you are a carer.

- Do you take care of a loved one on a daily basis?
- Would they manage in daily life without your help?
- Do you help them with dressing, bathing, or taking medicine?
- Do you help them eat or move?
- Do you give them medicine at night or change sanitary pads?
- Must another person care for your loved one when you are not present?
- Do you take care of things that your loved one was once able to do themselves?

Your loved one may be ill, disabled or elderly.

If you take care of washing, dressing and meals daily,
you are a carer.

If you meet certain conditions,
you may qualify for benefits and services from the municipality.

Your own situation and its assessment is not always easy. It can be difficult to know whether you are a carer.

The following lists will tell you who can be a carer and who can't be a carer.

#### Who can be a carer?

A carer can be a loved one's

- mother or father
- own adult child
- spouse
- relative
- neighbour
- friend.

#### Who can't be a carer?

A carer can't be

- a stranger
- a healthcare professional, hired to look after your loved one
- an underage child of the care receiver

A carer needs support in daily life. Therefore, it is important to know that you are someone's carer. The care receiver needs sufficient and proper caregiving. A carer can't be someone who has no desire to

or is unable to care for their loved one.

A carer must take care of
the wellbeing and interests of the care receiver.
Therefore, a carer can't act against
the interests of the care receiver.

# What is caregiving?

As a carer, you may have to take on new or unfamiliar tasks. Caregiving involves learning new things. You may need to, for example:

- give medicine
- feed
- help with bathing
- give moral support
- lift and move
- watch over your loved one.

All of these tasks are important. An elderly, disabled or ill person can't do these things themselves and needs help from another person. Taking care of a loved one may be tough. The situation may be new and difficult. You may be worried and nervous, because you have a new role as a carer.

You might not know straight away what you must do or what is expected of you.
You may have mixed feelings.
You may be anxious, angry or sad.
At the same time, you may feel a desire to take better care of your loved one.
All of these feelings are normal in a new situation.

Caregiving is always hard work.
It means serving another person,
and doing good things for them.
That is why it is done voluntarily.
A carer can receive help in caregiving.
You don't have to do everything alone.

In different cultures and countries, people have different attitudes to caring for their loved ones. Families may have their own ways of taking care of loved ones. In many cultures, grown up children, especially daughters, take care of their elderly parents. In some countries, parents live with their children until the end. In the past, it was also common in Finland for different generations to live together. Family still plays an important part in caring, even though Finns no longer live together with their relatives. If people did not care for their loved ones, society would face great difficulties. A carer has an important job to do.

Caregiving is different in different stages and in different families. Sometimes, caregiving means that a carer looks after their loved one constantly, around the clock.

This is the case when a loved one is unable to eat on their own, get dressed, go to the toilet or ensure their own safety. Sometimes, a carer takes care of their loved one in addition to having another job, and spends all their free time caregiving. Caregiving can continue for a few years or for an entire lifetime.

Caregiving changes a family's life.
Family life can change suddenly
if a loved one faces an accident, for example.
The situation may also develop slowly,
as a loved one ages.

Caregiving means that the familiar roles within a family stay the same. The carer and the care receiver continue to be spouses, for example. In caregiving situations, the parties involved are primarily parents, spouses and children. Carers can be, among others

- the parents of a disabled child
- a wife or husband taking care of their spouse
- women and men taking care of their ageing parents.

Caregiving means that a loved one can live in their own home for as long as possible. In this way,

the quality of a loved one's life remains good.

### The stages of caregiving

Caregiving can become part of a family's life at any time.

The situation may develop slowly or quickly. A loved one may need more help as they age.

A child who is born with a disability needs special care. A loved one may suffer a sudden seizure or face an accident.

Caregiving affects everyone in the family. Caregiving always involves a change of life, after a family member becomes ill or disabled.

Caregiving consists of different stages.
The length of these stages can vary,
and some families do not go through all of them.
The illness or disability of a loved one determines
how quickly or slowly
a carer goes through the stages.

The following list describes the different stages and what happens during them.

#### 1st stage: Preparation

In the preparation stage, a carer prepares for the upcoming caregiving situation. The carer is aware that in the near future, their loved one will need more of their help and time. The whole family's life will change. During this stage, it is important to gather information and ask questions.

#### How do you prepare?

- Find out about things.
- Ask questions and gather information.
- Talk about things with your loved one and with professionals.
- Make plans about how to handle the finances of your loved one or your own finances, for example.

#### 2nd stage: Starting caregiving

In this stage, caregiving begins. You will develop the methods with which you take care of your loved one. Find ways that best suit you, your loved one and your family.

#### How do you start?

- Try out and learn things that you will need to do.
- Seek out services and support that may help you in caregiving.
- Contact other carers and get to know them.
- Contact associations that offer support and services.

#### 3rd stage: Taking care of a loved one

In the third stage, caregiving is a part of your life, and you have developed a routine for it.

You have developed a certain way of taking care of your loved one.

Taking care of your loved one is a part of your life and that of your family.

With routines, the caregiving situation and your own life are in balance.

You manage things well and your family is happy.

How do you keep caregiving and your life in balance? It is important to get support for caregiving. The support can be both financial and psychological. You can get information about different forms of support from associations, for example.

You can also participate in the associations' activities by taking courses, for example.

Peer support is also important.

It means that you can discuss your situation with others who are in the same situation.

Take care of yourself.

Exercise and get enough rest.

Take up a hobby that you enjoy.

Take breaks from caregiving and ask others for help.

#### 4th stage: The end of caregiving

In the last stage, caregiving ends. Your loved one might move elsewhere, into a care home or sheltered housing, for example. Your loved one might also pass away.

How to get through the end of caregiving? Caregiving for your loved one ends and caregiving is no longer a part of your life. The end of caregiving is a change, even if your loved one seeks care elsewhere.

It is important to go through your feelings.

Talk about them with other people and share your experiences. If your loved one dies, mourn for them and go through your memories. Help other carers by sharing your experiences with them. Write them down for yourself.

# Support and services for carers

Carers have an important job.
A carer looks after their loved one and their wellbeing.
A carer must also look after himself, in order to have the energy to care for another person. This is why it is important to know about the kind of help that is available and about where you can apply.

A carer can get various services and benefits. You need to apply for them yourself. It is important to be active and find out which benefits are available. There is a wide variety of support and services available. Look for the kind of support that best suits you and your family.

#### You can receive support from the following places:

- your municipality
- the Social Insurance Institution of Finland, Kela
- associations
- churches

The following chapters will tell you more about support for informal care and other forms of support.

# What is support for informal care?

A carer can receive support for informal care.

Support for informal care is granted by your home municipality.

Support for informal care means that
a carer receives money for caregiving.

In addition, the carer gets days off,
during which the carer's loved one receives care
from a healthcare professional, for example.

Support for informal care also includes the services
that are given to the loved one.

The municipality may grant support for informal care if certain conditions are met.

These conditions are described below.

#### 1. The care receiver has an illness or disability

- The person receiving care has an illness or disability, which prevents them from taking care of themselves.
- The person's ability to take care of themselves has been reduced, and they can't manage on their own at home.

In such a situation, the person needs care or attendance.

#### 2. A family member can take responsibility for caregiving

- A sick person's loved one can take care of the person and take responsibility for their care, assisted by the necessary services.
- The carer is healthy and able to look after their loved one.

#### 3. The level of care in caregiving is sufficient

- In caregiving, a person receives care that is sufficient with regard to their health, wellbeing and safety.
- Sufficient care means that the person receiving care also receives other necessary services, which are provided by healthcare professionals, for example.

#### 4. Home is appropriate for caregiving

- The home of the care receiver is suitable for the purpose of caregiving.
- Authorities will assess whether caregiving at home is in the best interests of the care receiver.

It is then verified whether the person should stay at home rather than receive care somewhere else.



16

# How to apply for support for informal care?

Support for informal care must be applied for.
It is applied for from the municipality
in which the care receiver lives.
Support is applied for from the municipality's social services.
A municipality means a specific, limited area
in which people live.
It is an individual administrative unit

Contact the municipality's social services first and request for an application form for support for informal care. Fill in the form and return it to the social services. After that, professionals will assess your situation.

that provides services for its inhabitants.

A professional from the social services will come to discuss the situation.

The discussion will take place at home.

A healthcare professional will also be there.

This is an important discussion.

You can take your time to explain what daily life is like.

You can think about and explain what sort of help you need in order to look after your loved one.

After the discussion, the authorities will make a decision on support for informal care.

The decision may be positive or negative.

If the decision is positive, you will receive support for informal care.

In this case, you will sign an agreement with the municipality concerning caregiving.

After this, a representative of the municipality, the carer and the care receiver make a plan on the contents of caregiving. The plan is a part of the caregiver agreement. It is called a care and service plan. It tells you about, for example, what kind of services the care receiver needs and what services the municipality offers. It defines how a carer will look after their loved one and how much. The plan will tell you, for example, if the caregiving is to take place around the clock.

# What is included in support for informal care?

The following lists will tell you what support for informal care consists of both for the carer and the person receiving care. All the services and details are noted into the care and service plan. The plan outlines, for example, how the carer's days off are arranged, in other words who is to look after their loved one while the carer is not present.

Support for informal care for the person receiving care:

#### Care

- Support for informal care includes the care that the care receiver gets from the carer.
- The care receiver also receives care at times when their carer is on leave.

#### Services

- The support includes the municipality's social and healthcare services.
- The care receiver may get, for example, assistive equipment or housekeeping services, such as meal services, from the municipality.

Support for informal care for the carer:

#### Money

- Support for informal care includes a grant that is paid to the carer.
- The sum depends on how binding the care is, in other words, how much of their own time does the carer spend on caregiving.
- According the law the smallest grant for caregiving is 387,49 euros per month.
   In situations that call for more care, the grant is larger, 774,98 euros per month. (2016)
- The sum of the grant may differ depending on the municipality you live in.
- The grant is taxable income, so taxes are deducted from it.

#### Days off

- The carer gets days off, depending on how binding and demanding the care is.
- The carer is always entitled to two days off per month, or to three days off per month in the event that the care receiver requires a lot of care.
- The municipality will arrange care for the care receiver during these days off.
   The care can be arranged in a facility or in the care receiver's home.
   In these cases, the municipality will arrange for a substitute carer.
- The substitute carer can be another family member or loved one.
- The municipality will always decide on how the care will be arranged whenever the carer is on leave.
   The carer and the person receiving care can both express their opinions on the matter.
- The carer's leave is always arranged considering the best interests of the care receiver.
- Some muncipalities provide vouchers for organising a day off. The authorities give advice on how to use this voucher.
- If the caregiving is very demanding, the muncipality may grant the varer more than three days off. The muncipality may also grant additional short leave periods for recreation.

#### Pension security

- The grant in support for informal care increases the carer's pension.
   Pension means money that a person receives after they retire from work.
- Support for informal care increases a carer's pension when they are under 68 years old.

#### Insurance

- The municipality offers the carer insurance.
   This means that the carer is insured for accidents.
   An accident can be an incident in which the carer is injured.
- The insurance is valid during caregiving and during travel related to caregiving. If the carer is in an accident at such a time, they must see adoctor.
- The carer must ask the doctor for a certificate, in other words an E-statement for the insurance company.
- The carer must also immediately report the accident to the person with whom they have agreed about caregiving.

#### Other support

- The carer is assigned a support person, whom they can contact.
   The support person is called an office holder.
- The office holder will provide information and help related to caregiving.
- The office holder must, according to the law, guide and advise the carer in matters which concern support for informal care and related services.
- The office holder may be contacted, for example, when the carer is ill and unable to provide care at home.
- The municipality supports the carer's wellbeing.
   The carer can takea rehabilitation course, for example, or meet with other carers. These forms of support are recorded in the care and service plan.
- The carer may also request a well-being and medical examination from the municipality.
- As of the beginning of 2018, muncipalities will organise training for carers.

# Other support services for carers

- You may receive various services from your municipality to support caregiving.
- As these services are not granted automatically, you must apply for them or discuss them with the office holder.

  The services are not necessarily free of charge, and you may have to pay for them.

Think about your own situation. What takes the most of your energy and what might you need help with? After this, tell the office holder about it. They can best advise you.

If your loved one has become disabled, they are entitled to the services mentioned in the Act on services and assistance for the disabled. A doctor will confirm the disability and write a certificate.

This guide does not describe services for the disabled.
You can ask the office holder about them as well.

Examples of services that support caregiving:

#### Home care

 You can get help from the municipality for daily activities, such as bathing.
 Meal services can supply ready-to-eat meals.

#### Home nursing

 You can receive nursing assistance for taking care of your loved one at home.
 A home care nurse can, for example, treat wounds or give insulin shots.

#### **Daytime activities**

- The person receiving care can be admitted into sheltered housing for daytime activities.
- The sheltered housing facility arranges activities, such as outings and music.
- The care receiver is also served meals during the day.
- The municipality takes care of transportation for the care receiver.
- A taxi will take them to the sheltered housing facility in the morning and bring them back home in the afternoon.

#### Short-term care

- If caregiving becomes more demanding, contact the office holder assigned to you.
- Short-term care can be arranged for your loved one in a facility or group home.

#### Care equipment

- You will need different kinds of equipment for caregiving, such as sanitary pads and catheters.
- A doctor can write a certificate stating that the person receiving care needs these items.
- With the certificate, you can get the equipment at a low price or free of charge.

# Social benefits granted by Kela

Kela is short for Kansaneläkelaitos, the Social Insurance Institution of Finland.

Kela takes care of the basic security of Finland's inhabitants in various situations of life.

Kela pays out various benefits, for example.

The carer and the care receiver can apply for benefits from Kela if certain conditions are met.

The benefits include, for example, a care allowance, disability benefits, and rehabilitation benefits.

Ask a Kela office about what kinds of benefits exist and which benefits you might apply for.

Kela provides simple language brochures that tell you about Kela benefits.



### Work and caregiving

As a carer, you can also have a job. In that case, you need to think about whether you have enough time and energy. You need time and energy to go to work, take care of a loved one, and spend time with your family. It is important to also have some time to yourself.

Your municipality's services are especially important if you also have a job.

Talk to your employer about your situation.
Perhaps your current working hours
could be made more flexible.
Remote work might also be possible.
That means that you could work from home.
You can also apply for various kinds of leave from work,
such as job alternation leave or
part-time care leave.
That would mean fewer working hours
and thus more time for caregiving.
At the same time, however, your wages would be lower.
You can apply for financial support from Kela, for instance.
An elderly carer can also apply for a part-time pension.
In this case, you would work part-time and
be retired part-time.

An employee has the legal right to be temporarily absent from work if a family member suddenly falls ill or is in an accident.
You must always agree on the absence with your employer. Wages will not be paid for the time absent.

# Caretaker – take care of yourself!

It is wonderful to look after a loved one and help them.
Caregiving is love for another person.
Caregiving can also be tough.
The carer may become exhausted if they do not receive enough support.
As a carer you must also be willing to accept help and support.

Make sure that you stay in good shape. You will have more strength if you are healthy. Follow the following instructions in order to keep fit:

- eat healthily
- get enough sleep
- go outside
- exercise.

As a carer, it is good to go to the doctor for regular check-ups.

You may need to take care of your loved one around the clock. Your loved one needs constant help.

A carer has to learn how to do new things, which the care receiver did on their own before.

The personality of the care receiver might also change.

As a carer, you may need to look after the whole family and take responsibility for the family's life.

All of this takes its toll on a carer's strength.

A carer might not have any time to themselves.

All of their time is spent on caregiving and other work.

Personal time is important, nonetheless.

Everyone needs rest and recreation.

That improves your physical and psychological strength.

You will have the strength to take care of your loved one if you look after yourself.

It is not unnecessary to take care of your own wellbeing, it is rather necessary and useful.

As a balanced human being,

you will have more strength to help another!

Relax and let your mind drift somewhere else every once in a while. Think about things that make you feel stronger. Do you have a hobby that is important to you? Continue that hobby, if possible.

Below is a list of ideas for relaxation:

- 1. Do something you enjoy.

  Listen to music or read a book.
- **2.** Go outside every day.
- Remember to rest. If you don't get enough sleep, take a nap.
- **4.** Remember to use humour and laugh. Laughter is great medicine!
- **5.** Keep a diary. You can write about happy times and sad times in your diary.

- 6. Meet friends or relatives.
- **7.** Go downtown, do some shopping, see a movie or go to a concert.
- **8.** Spend time with your children or grandchildren. Play with them and tell them stories.
- 9. Grow flowers or look after a garden.
- 10. Praise yourself once a day!

## Support from other people

As a carer, it is important for you to get psychological support. Your immediate and extended family are important support networks.

Relatives help each other, and you can easily turn to them for advice.

When your family member or loved one falls ill, you need support from your loved ones and an opportunity to discuss the situation.

If your relatives live in another country, the support network may seem small. If your relatives live far away, you can turn to other carers. You are not alone in your situation. There are many carers in Finland who are in a similar position.

Other carers will understand you.
With them you can share your thoughts,
feelings and experiences.
This is called peer support.
They can also give you a lot of information on caregiving.
Many associations include peer groups for carers.

Joining a group may feel difficult.

Think of joining as something that will do you good. It will give you some time to yourself. If you are an immigrant, it is important to participate in a group. You can get to know other carers and hear about their experiences.

They know a lot about local services and benefits for carers.

However, it is not always possible to join a group.
It is also good to discuss caregiving
with your friends or
with a church employee, for example.
You will often find that your friends also have experience in caregiving.
When you discuss matters with others,
you will receive support and encouragement.

There are also professionals with whom you can talk confidentially. Professionals are not allowed to tell others about your private matters.

There are online peer groups for carers as well as various kinds of discussion forums. Through the internet, you can talk with carers from all over the world. The internet will also give you a lot of information on caregiving and your loved one's illness, for example.

If there is something in caregiving or in your own coping that concerns you, contact the office holder assigned to you.
Tell them about your worries.



### **Carer** associations

#### Omaishoitajat ja Läheiset -Liitto ry

The Central Association of Carers in Finland is an organisation for carers and their loved ones receiving care. It is a nationwide organisation that furthers the interests of its members by promoting the status of carers, for example.

The association gives its members support, guidance and advice.
In problematic situations, carers can also receive legal counsel.
The association can assist a carer in going on a holiday or taking a rehabilitation course.

#### Contact information

Omaishoitajat ja Läheiset –Liitto ry Hämeentie 105 A 18 00550 Helsinki Internet: www.omaishoitajat.fi Tel: 020 7806 599

#### Pääkaupunkiseudun Omaishoitajat ja Läheiset ry POLLI

The association of carers and loved ones in the capital region is known as Polli.

It is active in Helsinki and Vantaa.

Polli is a local association

that provides information, guidance and advice.

The association arranges excursions and parties.

Polli advertises its activities in its member magazine, which is published four times a year.

#### **Contact information**

Pääkaupunkiseudun Omaishoitajat ja Läheiset ry POLLI Pasilan puistotie 8 00240 Helsinki Internet: www.polli.fi

Tel: 040 5332 710

You can join the Central Association of Carers in Finland by paying a membership fee. You will then also become a member of the local association.

33

It is enough to sign up once. In 2017, the membership fee is 25 euros per year.

Local associations include carer groups. In these groups, you can meet other carers. Members are sent the Lähellä magazine, which appears four times a year.

### Other associations

In addition, the local association publishes leaflets about its activities.

Members also receive useful guides.

For example palveluopas and lomaopas.

The guide features a list of services that support caregiving.

There are also local associations outside the capital region. Find out which organisation is your local one. There are many across the country.



In Finland there are many associations and organisations. They each promote a particular cause.

Associations may consist of individual people or other associations.

Almost every illness and disability group has a dedicated association.

There are many non-governmental organisations that support carers.

Non-governmental organisations promote people's interests or help individuals.

Try to find an association whose activities suit you or your loved one.

If you are the mother or father of a child with a developmental disability, you can get a lot of useful information and support from Inclusion Finland KVTL and the Finnish Association on Intellectual and Developmental Disabilities. These associations have web pages with information in simple language.

#### The websites are

- www.kvtl.fi
- www.kehitysvammaliitto.fi.

If you are taking care of elderly parents, you can get information and support from the Central Union for the Welfare of the Aged, the Finnish Union for Senior Services, and the Alzheimer Society of Finland.

#### The websites are

- www.vtkl.fi
- www.valli.fi
- www.muistiliitto.fi.

If your loved one has mental health problems, you can get information and help from the Finnish Central Association for Mental Health, the Finnish Association for Mental Health, or Omaiset mielenterveystyön tukena (Family members in support of mental health care).

#### The websites are

- www.mtkl.fi
- www.mielenterveysseura.fi
- www.finfami.fi

Ask for more information on associations that might be useful for you. You will find more information from your local association of carers, for example.

### Churches

There are carer groups in many churches.
The groups can provide you with peer support and you can spend time together with group members. You can discuss things with people whose situation is similar to your own.

Churches arrange activities for carers, such as recreational events, lectures and camps.
Churches offer spiritual support as well.
You can turn to a church employee to discuss personal issues confidentially.
Ask your local church for more details about its activities.

