

SUPPORT GROUP FOR INFORMAL CARERS

Support for those caring for loved ones



Welcome to the Red Cross' Support Group for home carers!

One in five people in Sweden regularly cares for and supports a loved one. The support group for carers provides an opportunity for you to gain more knowledge regarding your rights as a carer and how to handle the practical challenges you will be facing. The focus is on the life situation of the carers, the role of an informal carer and support services available to you.

Support group is a closed discussion group which meets together with discussion leaders. The group looks at the needs of its participants and focuses on what it is like to be an informal carer, rather than the reasons why they have become care givers. The group meets regularly on at least eight occasions over the course of a maximum of six months. At the end of this time, opportunities are usually offered for the participants to continue to meet under different forms.

The group offers the participants a chance to reflect on their situation. The sense of belonging and understanding of others provides comfort and strength. Here they can express their thoughts, ventilate, and share experiences, they are given an opportunity to reflect on themselves in the light of other people's experiences. Sharing experiences and thoughts leads to new perspectives. Participating is not just about receiving support, but also giving support.

Each group is unique, and sometimes things happen in life that changes the focus of the meeting to something other than what was originally planned.

This material contains suggestions for how to structure the meetings using different themes, and on the last page you will find tips on where to find more information. All themes are numbered, but the number does not indicate the order of the meetings. The group can change the order of the themes or use more than one meeting to discuss a particular theme. Participants can also suggest other themes that may feel more relevant. It is important to see the needs present in the group.

At the end of each group meeting participants can be given questions to reflect on ahead of discussions at the next meeting. These are highlighted in italics.



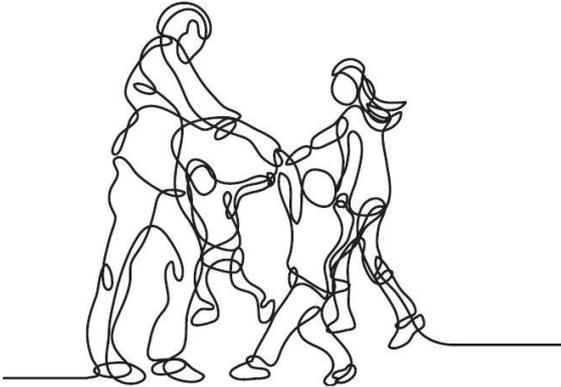
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1. Informal carers Who are we?	4
2. Informal carers What are our rights?.....	5
3. Practical everyday assistance	6
4. Informal carers and carers - one or more roles?	7
5. How do you view your role as informal carer	8
6. Informal carers needs – What do you need?.....	9
7. Health and self-care.....	10
8. Providing aid and care.....	11
9. Financial matters relevant to you as informal carers	11
10. At life's end.....	11
11. The final meeting.....	12
Websites and phone numbers	13

1. Informal carers

Who are we?

Introduce yourselves and describe your personal expectations of attending the group.



What are you hoping to get out of being here? Do you need to change your own situation? Are you looking to influence support plan aimed at your loved one or yourself? Do you need to talk to people who understand your situation? Do you want to offer support to people who are in a situation similar to yours?

The group leader will inform you of how the group works. They will provide practical details and information regarding the material. You will also receive information regarding the Red Cross and the methods being applied.

The purpose of the group is to support informal carers in their role and life situation by helping them

- reflect on their own situation
- meet people in a similar situation
- give insight on the rights of informal carers

The leader will explain the structure of the group, the role of the leader, and the laws that regulate support. All participants are given a chance to speak, decide on content, practical issues, and group confidentiality. Confidentiality means that members speak with each other when they meet and not about

each other between meetings. Words spoken in the room are to stay in the room. Becoming a part of a group and discussing your situation can feel like a big step. Each participant will be able to proceed at their own pace.

Terminology

- **An informal carer** or caregiver is the person who regularly cares for, helps, and supports a loved one.
- **The loved one** is the person who needs support due to illness, disability, or old age.
- **Care** refers to the healthcare, help and support provided to the loved one by their family member

Discussion topics

- What does a regular day in your life look like?
- Who are the important people in your everyday life?
- What do you see us having in common in this group?
- What separates us?

The meeting ends with a discussion where everyone gets a chance to speak

- How does it feel now?
- What have we agreed on?
- Which meetings or themes feel most important to you?

2. Informal carers

What are our rights?

The law states that society is responsible for the sick and those in need of help. The efforts of informal carers should be voluntary. According to Swedish law, there is no obligation to provide care and support for adults. There are provisions regarding children in the law on parenthood. It is all clear and simple, but what does the reality look like? Can you get the support you want?

Discussion topic

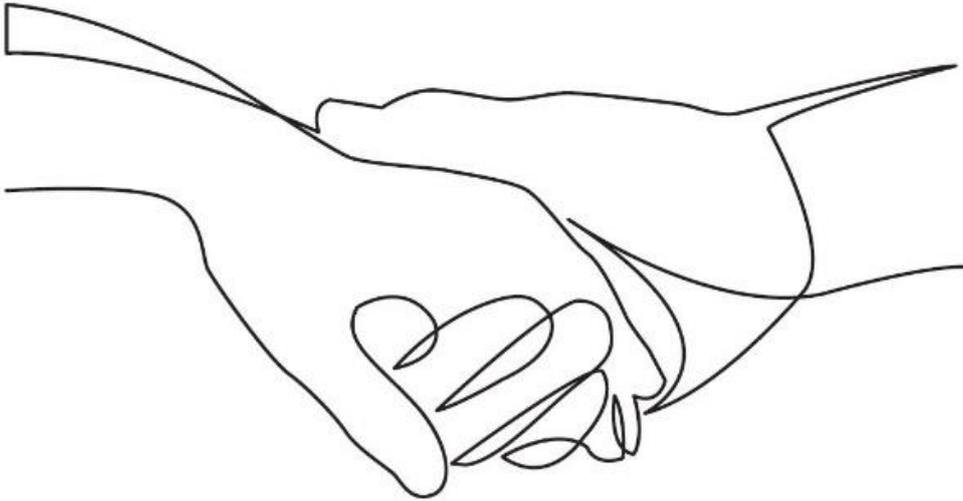
How do you view your own voluntary work, and what does this work look like?

Discussion topics

- What sort of aid do you need?
- What are your expectations regarding the aid you would wish to have?
- What kind of aid can the local authorities offer?
- Is there anything in the support offered by the local authorities which you would benefit from?

The municipality is obliged to offer informal carers individually adapted support plans to provide aid and prevent ill-health: *The social welfare service is obligated to offer aid to support individuals caring for a loved one with a long-term illness or due old age, or who supports a loved one with a disability.* (Social Services Act, Chapter 5, Section 10) Aid shall contribute to better health and well-being. What services are offered to you as an informal carer by your local authority?





3. Practical everyday assistance

We address all the issues informal carers have to deal with, such as mobility aids and equipment, medication, assistance, how to apply for grants and how to manage the finances. We will also look at how to apply for grants for special accommodation, mobility service, relief, and respite care.

The help that a loved one will require changes over time, making it necessary to define what practical help is needed now and in the near future. Share your experiences of this with the group.

Discussion topics

- Are you currently receiving help to make your everyday life easier?
- Is there something you need help with right now?
- Where do you turn to for help?
- Do you need more information?
- Would you like to spend more time on any of the topics we have discussed today?



4. informal carers and carers - one or more roles?

Relationships change when the loved one is no longer just your husband, wife, partner, child, or parent. It is sometimes hard to define when an informal carer becomes a caregiver. As family roles change, so too do the relationships, which often also applies to the relationships with those around you. We are talking about the act of balancing life as it was with what it has become.

Discussion topics

- What was your life like before and how has it changed?
- Was there a particular point in time when you became a caregiver?
- What does your loved one expect of you?
- What is your view on your role as an informal carer and how do others view you in this role?
- What's important for you so that you can feel that expectations on you are reasonable?

This is appropriate as a topic for reflection.

6. Informal carers needs – What do you need?

Many Informal carers feel that life changes, that the chance to continue doing things that have been important to them and provided a sense of well-being is limited. It is easy for the needs of the loved one to always take priority. That is why the focus is now on you, your feelings, desires, personality and wishes. In our everyday lives, there are different needs that we need to satisfy, aside from the essential ones, such as eating, drinking, and sleeping. Physical activity, personal hygiene, social interactions and feeling appreciated are factors important to one's well-being, as is the feeling of security. Knowing that you are not alone in your feelings is important.

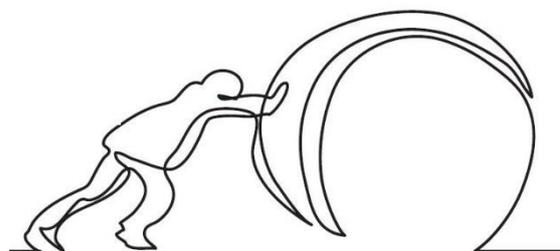
Signs of stress

- fatigue
- having trouble sleeping and waking up early in the morning
- difficulty in relaxing
- difficulty in concentrating
- feeling irritation and impatient
- getting stuck in negative thoughts and feelings of dejection
- avoiding social contacts

Experiencing stress is a part of life. But if the stress persists for a long time, it can be harmful to you body, making recovery and rest all the more important. The largest contributing factors to stress are demanding situations in which you feel that you have little control over and feel alone in dealing with them. If the demands are high and overpowering, it is easy to lose control of the situation. A lack of activity and social interactions can also be stressful.

Discussion topics

- Do you recognise any of the signs of stress?
- What can you do as part of your everyday life to reduce your stress levels?
- What makes you feel good?
- Do you have any tips for achieving a better life with balance and space?
- Describe a situation that you find stressful.
- Are there any alternate ways of handling that situation?



If you have lived as an informal caregiver for a long time, you often don't know who you are anymore!"

Sten

7. Health and self-care

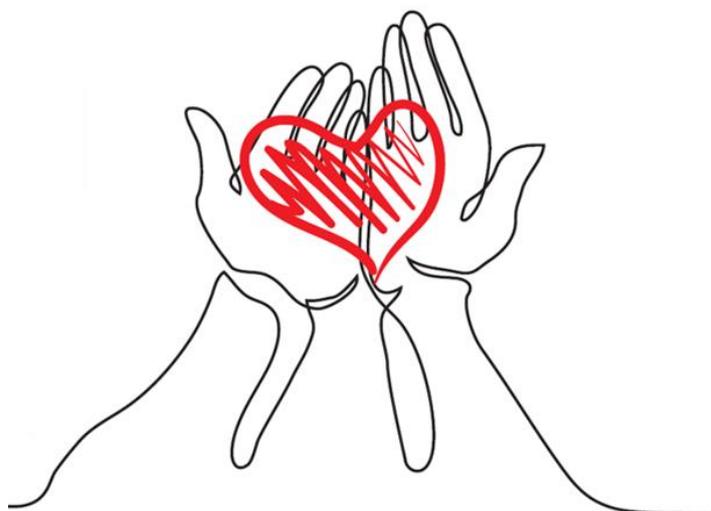
Discuss the term “health” with the group. What does health mean to you?

There is a Swedish proverb which roughly translates as “Good health is quiet”, which means that we only become aware of our health once it is taken from us and we fall ill. There is a link between the sense of context and good self-perceived health. Some people manage just fine despite great pressure because they find the situation meaningful, understandable or manageable.

Here are a few factors which may be crucial to the health of Informal carers:

- loved ones being offered good care and support
- the knowledge that help and support is available, how to request it and what you are legally entitled to
- working interactions between health and social care institutions
- treatment with a great deal of respect
- time for oneself and chosen activities

Time to yourself and your own activities might not be possible without someone to take over for a while. The local authorities offer various forms of home relief, such as different alternatives for accommodation or daily activities for loved ones.



Discussion topics

- Do any of the factors listed above affect your health?
- Do you have any opportunities to make time for yourself?
- How should one act when a loved one is not sympathetic to your own needs?
- What do you imagine yourself doing if you had a day “to yourself”?

THEMES FOR ADDITIONAL MEETINGS

8. Providing aid and care

It is important that the loved one receives training in being as independent as possible. An illness or injury can affect one's abilities in a variety of ways, and things that were previously taken for granted are no longer possible.

Occupational therapists and physiotherapists are important resources available to informal carers giving care and support to a loved one. Adjustment, training, information and knowledge may be required to help support and strengthen both the loved one and the carer.

Invite a physiotherapist, occupational therapist, dental hygienist, speech therapist or any other expert to your group. It always helps to start conversations if questions are prepared in advance.

Discussion topic

What would we like more information about?

9. Financial matters relevant to you as informal carers

Caring for and supporting a loved one can entail changes to your everyday life. What would happen if you left your job or worked fewer hours to make time for caregiving? What

would happen to your finances and your future retirement?

Invite an expert who can provide insight and guidance.

Discussion topics

- Have you thought about quitting your job or working fewer hours?
- Do you know what would happen to your pension if you worked less?
- Are there any other solutions?

10. At life's end

Losing a loved one can be incredibly taxing. Regardless of whether death comes suddenly or is expected, we are usually unprepared for the time immediately following the passing. What happens now and what am I supposed to do?

Dr, Ulla Söderström writes In The care guide: "Grief is a powerful emotion which can cause us to mature, but it can also change one's life to the point where it feels empty and incomplete."

Read Ulla Söderström's writings or invite a guest to talk about grief.

What do you know about grief, funerals, probate, wills and inheritance? Invite an expert to a meeting. Prepare questions in advance.

Discussion topics

What would you like to know more about?

11. The final meeting

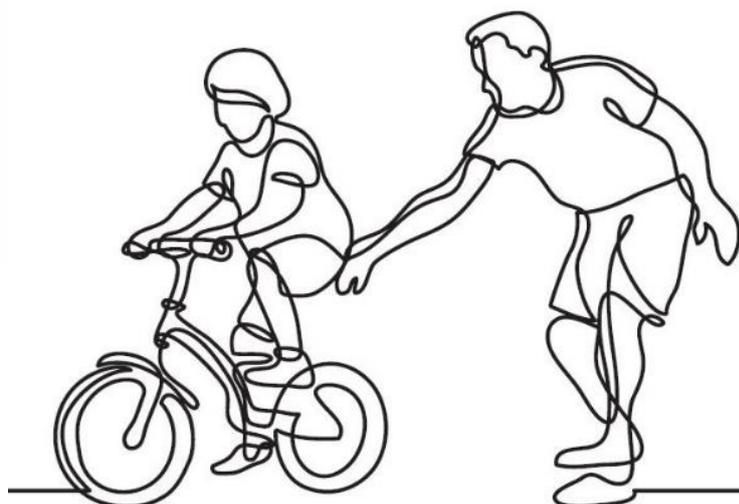
In the last meeting review the goals and expectations from the group's first meeting and summarize your impressions and experiences.

Discussion topics

- Did the meetings correspond to your expectations?
- What has worked well?
- Do you have suggestions for what could be improved upon for future groups?
- Have you gained any new "tools" for coping with your everyday life?
- What is your view of your role as an informal carer now?
- Do you feel more knowledgeable about Social services?
- Have you received or applied for more interventions?

Will the group carry on in some other form?

- Does the group wish to continue meeting?
- In what form and to what extent?
- What would you like gain from a continuation?



Thank you for participating in the group for informal carers and for sharing your experiences!

Websites and phone numbers

National Board of Health and Welfare

www.socialstyrelsen.se/stodtillanhoriga

The Swedish Family Care Competence Centre, SFCCC

is a resource for developing support for informal carers. The organisation creates and develops meetings which bring together:

- informal carers, users, and their organisations
- professionals within social services and elderly care
- assessment officers
- researchers

www.anhoriga.se.

Anhörigas Riksförbund Carers National society

A non-political, secular independent organisation that offers support to formal carers and caregivers regardless of age, gender or diagnosis of the person receiving care.

www.anhorighandboken.se

Anhörigas Riksförbund has a telephone and email service for advice and support for family members called Anhöriglinjen (“The Family Member Support Line”).

Telephone: +46 (0)200-239 500

Telephone hours: Monday, Tuesday, Thursday, and Friday 10:00–12:00 and 13:30–15:00,

Wednesday 19:00-21:00.

Email: info@anhorigasriksforbund.se

Healthguide

Provides information about diseases and health, as well as how to seek care.

Call 1177 for healthcare information.

www.1177.se

Vårdguiden’s information regarding support for family members:

www.1177.se/Regler-och-rattigheter/Anhorigstod/

Literature

The group leader has a book list with information about each title.

Some titles are also available in audio and e-book form.

Anhörig i nöd och lust (Vårdförlaget) by Lennart Johansson

April in Quiet Despair (Albert Bonniers Förlag) by Susanna Alakoski,

Litet syskon (Gothia Förlag) by Christina Renlund, psychologist

Vara anhörig: bok för anhöriga till psykiskt sjuka (Forum) by Åsa Moberg

Unraveling the Mystery of Health: How People Manage Stress and Stay Well (Natur & Kultur) by Anton Antonovsky

The Longest Round (Forum) by Edna Alsterlund

När kommer våren? (Nomen Förlag) by Ingrid Oscarsson Ling

Boken om E (Albert Bonniers Förlag) by Ulla Isaksson

Tuesdays With Morrie (Månocket) by Mitch Albom

THE WORLD'S FOREMOST DISASTER ORGANISATION

The Red Cross is the world's leading disaster relief organisation. We are in place before, during and after a disaster. Whether it's a natural disaster, conflict, or other crisis. We shall prevent and alleviate human suffering wherever and when it occurs, protect life and health, and ensure respect for the value of every human being, especially during times of armed conflict and other emergencies.

We work according to seven fundamental principles: Humanity, Impartiality, Neutrality, Independence, Voluntary, Unity and Universality.



Basic principles in one minute

1. The Red Cross's mission is to prevent and alleviate human suffering (humanity).
2. We make no distinction between people – we do not discriminate in terms of nationality, ethnicity, religion, social status, or political opinions (impartiality).
3. Nor do we take a stand in conflicts or differences of opinion (neutrality).
4. The Red Cross is independent and cannot be governed, we consult and interact with others, if they accept that we work in accordance with our fundamental principles (independence).
5. Getting involved in the Red Cross is voluntary, as is accepting help from the Red Cross (voluntary).
6. In each country there can only be one national society, we are the Swedish Red Cross (unity).
7. We belong to a worldwide movement in which we support each other (universality)



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