CARING FOR SOMEONE WITH DEPRESSION:

Caring for two?

Learn to care for yourself while caring for a loved one with depression

This brochure has been developed by the European Federation of Associations of Families of People with Mental Illness thanks to an in-kind support sponsorship from H. Lundbeck A/S as a contribution to the public health debate.
You care. That’s why informal carers like you spend an average of 22 hours a week directly supporting your loved one. It’s at least a part-time job. For some a full-time job — on top of your usual activities. But the worrying for your loved one never really ends, does it? Your contribution is invaluable on the path to recovery.

Depression is a complex condition with a broad mix of symptoms — emotional, physical, cognitive and social (see page 10) — and it affects people in different ways. Worldwide, it is the leading cause of disability and affects 350 million people. Prevention, treatment and recovery are most efficient when there is a collaborative effort involving patients, their family, friends, service providers, healthcare professionals and employers.

This guide is intended to support you in taking care of yourself and taking care of your loved one. It is based on advice from experienced caregivers at EUFAMI. In the first section, we offer you four steps to take good care of yourself. In the second section, we have three steps on caring for your loved one.

We find it difficult to help the person with depression and often feel that we aren’t capable of helping overcome the pain, sadness and discouragement. But it helps always being present and never losing hope.
Care for yourself

Put on your own oxygen mask before helping others

It is only by taking good care of yourself that you can begin to take good care of others. This is the first step towards helping the person affected by depression. Caring for yourself should neither be complex nor demanding – focus on the simple things that give you energy. Here are four steps to help you take care of yourself while taking care of a loved one suffering from depression.

STEP 1: Make sure you take the time to care for yourself

We know you often run out of time but taking good care of yourself is key to your own well-being and your ability to care for others.

You do not need to add a demanding exercise and diet regime on top of your caregiving responsibilities.

Take care of your mental health

Feed your mind positive thoughts to increase your confidence:

"I made a valuable contribution. Now I will reward myself with a long and refreshing shower."

"I’m doing the best I can and it makes a difference."

"I can make time for a 15 minute walk."

Take care of your physical health

- Allow yourself to prioritize your own well-being.
- Make sure you get your sleep. Create a bedtime routine, go to bed around the same time every night and set your alarm clock for the same time every morning.
- Plan time each day for small rewarding activities you enjoy – reading a book, having lunch with a friend, getting a massage, cooking a simple meal.
- Eat more of what is good for you and less of what is bad for you.
- Try to get some regular physical activity – perhaps a walk every day. Or swimming, yoga, dancing – whichever you enjoy.
It is no secret that there will be difficult times in caregiving. In fact, the role of a carer can be full of ups and downs. Caregiving often results in chronic stress that can threaten your physical and psychological health. This is why it is important to get to know your own limits and be mindful of the warning signs.

Watch out for warning signs

When should you start worrying that you are putting too much pressure on yourself in your role as a caregiver for someone with depression?

Look out for these potential warning signs:
- Have you chosen not to go out recently (maybe as a consequence of your loved one also having cut social interaction)?
- Have you become more tired recently?
- Do you have trouble sleeping?
- Have you become more irritable recently?
- Have you stopped inviting friends or family over?
- Have you stopped making plans for the future?
- Do you feel distracted when trying to read a book or watch a movie?
- Have you lost or gained a lot of weight?

Everyone has their own warning signs. Learn to recognize your own boundaries.

STEP 2: Safeguard your own boundaries

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STEP 3: Managing the difficult times as a caregiver

Use these tips to prepare yourself in advance to help manage caregiver stress:

Accept help. Prepare a list of things that others can help you with and let them choose what they would like to do from the list. Map your support system and don’t be afraid to ask for help.

Set realistic goals. Break large tasks into smaller steps that you can do one at a time. Prioritize, make lists and establish a daily routine. Begin to say no to tasks that are draining.

Keep the lines of communication open with your loved one as well as with other caregivers.

Communicate constructively. State the facts; tell people how things affect you; tell them what you need from them. Avoid the blame game.

Seek social support. Set aside time each week for connecting with family and friends.

Set personal health goals. For example, set a goal to establish a good sleep routine, drink plenty of water or find time to be physically active (see page 4). Don’t lose sight of your personal goals and healthy routines.

Talk to your doctor. Talk about your responsibilities as a caregiver and how it’s affecting you. Ask your doctor for support recommendations and advice.

Take a break. Reach out to your community* to see what resources are available to enable you to take the time off that you deserve or need. Many of EUFAMI’s members can help you find the resources to do that.

* Find your community on: http://www.eufami.org/members
What is constructive communication?

Constructive communication is a way of being able to get across your thoughts, feelings and needs in a positive and assertive way. It is designed to help you avoid sounding critical of your loved one at a time when they are extremely sensitive. It also prevents you from saying things that you would not normally say if you were not overly tired or frustrated.

Based on 3 steps (1. State the facts, 2. State how it affects you, 3. Say what it is you need), it is simple and easy to learn. Try using constructive communication by filling in the speech bubbles below based upon your own experiences.

But of course, this is only one half of the story. A good communicator is also a good listener.

1. **State the facts**
   "I've noticed you are having more trouble getting out of bed lately."

2. **State how it affects you**
   "I am worried about you."

3. **Say what it is you need**
   "I need you to tell me whether there's something I can do. I need to know whether I can invite some friends over."

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**STEP 4: Start building your personal support system**

List friends, family and colleagues who can and will help you. Make sure you take advantage of the many resources and tools available to help you provide care for your loved one.

**COLLEAGUES** & **HR SERVICES AT WORK**

**FAMILY AND FRIENDS**

**APPS AND ONLINE SUPPORT**

**PEER SUPPORT & ADVOCACY GROUPS**

**HEALTHCARE PROFESSIONALS & SOCIAL WORKERS**

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1. Read about existing online support on page 16.
2. Read about peer support and advocacy groups on pages 18-19.
Care for your loved one

**STEP 1: Identifying symptoms of depression**

Is your loved one affected?

Contrary to common belief, depression is not synonymous with incapacitating sadness. Familiarize yourself with its wide range of symptoms.

**Symptoms of depression to look out for in your loved one**

**Affecting your mind (cognitive)**
- Difficulty concentrating
- Indecisiveness
- Forgetfulness
- Slow thinking speed
- Difficulty problem solving
- Difficulty planning

**Affecting your mood (emotional)**
- Sadness
- Anxiety
- Lack of enjoyment
- Hopelessness
- Guilt

**Affecting your body (physical)**
- Tiredness
- Changes in eating patterns
- Sleeping problems
- Stomach problems
- Headaches
- Chest pain

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When you realize or strongly suspect that your loved one is suffering from depression, you can help by:

**Keeping lines of communication open**
The most important thing is not what you say but that you are there.

### Don’t Say
- What’s wrong with you?
- I thought you were stronger than that.
- No one ever said life was fair.
- Everyone goes through this.
- It’s just in your mind.
- I can’t relate to your situation.
- Just snap out of it.
- Look on the bright side.

### What You Should Say
- I may not understand exactly how you feel, but I care about you and want to help.
- This is not your fault.
- You’re not alone.
- We’ll do this together.
- I’m proud of you.
- What can I do to help?
- Choosing treatment does not make you weak.
- Thank you for sharing and being honest.
- You are important to me.

### Encouraging your loved one to seek professional help
Depression is recognized as a mental illness\(^1\) and it affects people in different ways. Encouraging your loved one to seek professional help is the most important step on the road to recovery.

Offer to make the appointment. Offer to go with your loved one to the doctor. Before you go to the appointment together make a list of emotional, physical and cognitive symptoms (see some examples on page 10).

Encourage your loved one to be open and honest when talking to the doctor. Emphasize that this is a positive step in taking control of the condition and a sign of strength, not a weakness.

### The most difficult thing about sharing your life with a partner with recurring depressive episodes, is perhaps you feel like it becomes your responsibility to estimate when to raise the alarm and get medical help. Is it just a little dip, or is it more? How can you make that assessment, together with, but sometimes also in name of your partner, that remains difficult.

*Partner of someone suffering from depression*

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1. WHO has recognised depression as a common mental disorder. It is the leading cause of disability worldwide. Read more about it on: [www.who.int/mediacentre/factsheets/fs369/en/](http://www.who.int/mediacentre/factsheets/fs369/en/)
Supporting your loved one’s recovery process

Have a discussion about recovery goals and what steps should be taken to reach them. Focus on small goals that are not overwhelming. Watch out for signs of relapse as the recovery pathway can be long - if you notice signs of relapse, suggest a new appointment with a healthcare professional or care provider.

Treatment, including talk therapy and medication, takes time and your support during this period will be invaluable, especially by helping your loved one manage their disease and symptoms and in preventing a relapse. Encourage your loved one to stick to their treatment plan and discuss with them what role you can play in ensuring that prescribed medication is taken and appointments kept. Any adjustments to these plans should be discussed with a healthcare professional.

My best piece of advice to someone who is taking care of a loved one affected by depression is to stay alert for all the signs of relapse and to have a preventative plan of action ready.

Mother of a person with depression

Fighting stigma with information

Caregivers and people with depression also struggle with stigma and prejudice.

If you want to fight stigma, you can reach out to your local group or community* and ask how you can contribute.

Depression and suicidal thoughts

When a person is going through a major depressive period, the risk of suicide is at its highest. 3.2% of people in this situation are sadly successful in committing suicide.1

If the worst happens, please realize that it is not your fault.

Potential warning signs of suicide risks2

<table>
<thead>
<tr>
<th>Sign</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Reckless behaviour</td>
<td>(no longer fearing death, reckless drinking and/or drugs taking)</td>
</tr>
<tr>
<td>Strong anxiety</td>
<td></td>
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<tr>
<td>Talking about wanting to die, talking about suicide</td>
<td></td>
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<tr>
<td>Feeling hopeless, feeling helpless, like a burden to family and friends</td>
<td></td>
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<tr>
<td>Unusual preoccupation with death or deadly objects</td>
<td></td>
</tr>
<tr>
<td>Hiding away from society (the bedroom door is always closed)</td>
<td></td>
</tr>
<tr>
<td>Making plans in preparation of death (e.g. organising finances, giving away possessions or personal items)</td>
<td></td>
</tr>
<tr>
<td>Writing a suicide note</td>
<td></td>
</tr>
</tbody>
</table>

Things you could do when you think there is a risk of suicide²

<table>
<thead>
<tr>
<th>Action</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>If your loved one is at acute risk, immediately contact emergency services, your medical team or a suicide hotline</td>
<td></td>
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<tr>
<td>Make sure you and your family/close friends know the warning signs (see above)</td>
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<tr>
<td>Create space for your loved one to share their thoughts of suicide and reassure them that they are not alone</td>
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<tr>
<td>Keep the immediate environment safe by removing any objects that could help your loved one commit suicide and make sure someone is with her/him</td>
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<tr>
<td>Make a list of helplines and emergency contacts from your healthcare team. Distribute it to relevant friends and family</td>
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<tr>
<td>Encourage your loved one to contact helplines and their medical team</td>
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<tr>
<td>Keep at home an information sheet with the medical history, information about the treatment being taken and about health insurance</td>
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STEP 3: Finding online support

**Websites**

depnet.org
This website aims to support all those touched by depression by providing relevant, unbiased information and a platform for communication.

Rethinkdepression.com
Rethinkdepression.com continually posts the latest useful information about depression and how people can experience the disease. The site also provides information and tools to better equip friends, family and employers to support people with depression and understand the impact the disease has on themselves.

**Apps**

Myhealthapps directory
Myhealthapps directory has identified a variety of apps on different disease areas, including depression. Have a look and select the one that seems best for you.

iFeel app
iFeel aims to predict a depressive episode, giving you and your loved one enough time to take preventative measures.

It was developed in collaboration with people affected by depression, professional service providers and carers.

**Organisations supporting carers**

eufami.org
Only a click or call away from you, EUFAMI’s local members offer:

1. Helplines and chat lines often with peer-to-peer support. They’ve been there themselves, they know what you’re going through – and they want to help
2. Local face-to-face meetings
3. Website with resources
4. Training course to learn more about mental health and how to care for it
5. Support to help you navigate the healthcare and social system for services and financial support
6. Platform and communication tools to fight stigma

You can find your local support network on pages 18-19.
Our member organisations which you can reach out to for support

Austria
- HPE - Hilfe für Angehörige Psychisch Erkrankter
  - facebook.com/hpe.AT
  - facebook.com/pages/OJO-Kindheit-im-Schatten/14183997586
  - hpe.or.at

Belgium
- Similes VI - Federatie van Vlaamse SIMILES kringen v.z.w.
  - facebook.com/simileszw
  - similes.be

METIS Europe asbl
  - facebook.com/METIS-Europe-187549374598636/
  - metis-europe.eu

Cyprus
- KIPRODIPSA - Advocacy Group for the Mentally Ill
  - facebook.com/pages/JoJo-Kindheit-im-Schatten/141839997586
  - jojo.or.at

Czech Republic
- SYMPATHEA - Celonárodní Organizace Příbuzných Duševně Neschopených
  - facebook.com/psychosocialdisabilities
  - ozma.org.cz
  - ozma.org

Denmark
- Bedre Psykiatri (BP) - Landforeningen Pårørende til Sindslidende
  - facebook.com/BEDRE.PSYKIATRI
  - bedrepsykiatri.dk/

England - UK
- Rethink - Mental Illness
  - twitter.com/RethinkCharity
  - rethink.org

Finland
- FinFami - Omaiset Mielenterveystyön Tukena Keskuslilitto Ry
  - twitter.com/FinFami_omaiset
  - facebook.com/finfami
  - finfami.fi/

France
- UNAFAM - Union Nationale des Amis et Familles de Malades Mentaux
  - twitter.com/Unafam
  - facebook.com/unafam.oficiel
  - unafam.org/

Germany
- BAPK - Bundesverband der Angehörigen psychisch Kranker
  - facebook.com/pages/Landesverband-Bayern-der-
    Angehörigen%20Psychisch-Kranker-LAPK-
    de/46392290318072

Greece
- EDRA
  - twitter.com/EDRAStochori
  - facebook.com/EDRAStochori

Holland
- SOPSI Athens - Panhellenic Association of Families for Mental Health
  - facebook.com/sopsi

Republic of Ireland
- Shine - Supporting People Affected by Mental Ill Health
  - twitter.com/ShineIreland
  - facebook.com/pages/Shine-Supporting-People-Affected-by-
    Mental-III-Health/48814649226

Israel
- OZMA - The National Forum of Families of People with Mental Illness
  - facebook.com/psychosocialdisabilities
  - ozma.org.il

Italy
- ARAP - Associazione per la Reforma dell’Assistenza Psichiatrica
  - arap.it/

Lithuania
- LSªGBP - Lietuvos Sutrikusios Psichikos Žmonių Globos
  - facebook.com/LSPZGB?

Malta
- MHA - Mental Health Association
  - twitter.com/mha_mt

Netherlands
- Stichting Labyrint-In Perspectief
  - twitter.com/LabyrintPerspect
  - facebook.com/StichtingLabyrintInPerspectief

Northern Ireland - UK
- MindWise
  - twitter.com/MindWisenv

Portugal
- ENCONTRAR+SE - Associação para a Promoção da Saúde Mental
  - twitter.com/ENCONTRARSE

Russia
- New Choices
  - facebook.com/ODDH-Novye-
    Возможности
  - newchoices.org.ru/

Scotland - UK
- Support in Mind Scotland
  - twitter.com/supportinmindscot

Spain
- Consalud Mental - Confederacion Salud Mental España
  - consaludmental.org

Slovenia
- HUMANA - Zdrrojenje Svojev pri skrb za Mentalno Zdravje
  - facebook.com/humana

Slovakia
- OZARA - Nacionalno Združenie za kakovost Življenja
  - twitter.com/OZARA

Sweden
- Schizophrenieförbundet
  - facebook.com/Schizophrenieförbundet

Switzerland
- VASK - Vereinigung der Angehörigen von Schizophrenie-
  - facebook.com/VASK
  - vask.ch/de

Wales - UK
- HAPAL - for Recovery from Serious Mental Illness
  - twitter.com/HAPAL
  - facebook.com/HAPAL