Online support for carers

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- Professor, Linnaeus University, Kalmar
Topics

Part 1
• Introduction to online carer support

Part 2
• How to support carers online
• Carers’ experiences of online support

Interaction – your experiences and knowledge
Introduction to online carer support
• The Innovage project and the Swedish pilot study

• The InformCare platform through the eyes of fictive persons

<table>
<thead>
<tr>
<th>Sarah</th>
<th>Jack</th>
</tr>
</thead>
<tbody>
<tr>
<td>Retired</td>
<td>A working carer</td>
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<tr>
<td>A carer to her husband Michael</td>
<td>Supports his father Tim at a distance</td>
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The Innovage project

**Innovage** – an EU-project aiming to improve quality of life of older people and their carers in Europe.

**Web platform "InformCare"** - online support for carers.

The project was coordinated by the Italian Institute on Health and Aging (INRCA)

The whole Innovage-project is led by professor Alan Walker, University of Sheffield, UK.

http://www.innovage.group.shef.ac.uk
The Swedish carers-tested the InformCare platform for 3 months

• heterogenous sample (different diagnoses, disabilities, former carers, cared for person in a nursing home)
  
• 44 carers (informed consent)
• 10 men, 34 women

• Retired carers and working carers (mean age 64,7)
• Caring for spouse or partner (N=30)
• High educational levels (First stage of tertiary education N=21)
What can you find on InformCare?

**Information**
- **The most common** illnesses and disabilities amongst older people
- **Care** in daily life,
- **Help and support** available in society
- **Strategies** for carers to cope with the carer situation

**Interactive services**

**Social forum**
News, themes to discuss, links, materials. Comment on other carers posts.

**Social network**, similar to Facebook, Possibility to communicate with others in a similar situation.

**E-mail support**
counselling, information, emotional support

**Chat** – general and private

**Video chat**
Home care
Homecare services can include assistance with shopping...

Coping with caregiving
Being a carer sometimes makes it difficult to take care of yourself. Priorities are changing disease condition progresses and looking after yourself takes usually last place on a long list of heavy duties. Caring for a loved one isn’t an easy task, but it is important to understand the value of being a carer and living well...

Family reconciliation
When you are a carer, sometimes you find yourself in a position where you try to combine different family roles: as a parent, as a spouse, as a child and as carer. Reconciliation between family relationships and caregiving is a difficult task...

Work reconciliation
Working while caring isn’t an easy task. Employers and fellow employees might just not get it! Trying to be on time with work tasks and to be also a devoted carer generates stress, not always easy to manage. A key factor to reconcile work and care is to raise awareness among your colleagues and employers...
Lagar och regler
Stöd som finns tillgängligt för närstående och anhöriga.....

Att hantera sin situation som anhörig

Att balansera olika roller i familjen
Som anhörigvårdare befinner man sig ibland i en position när man försöker förena olika familjeroller som förälder, som partner, som ett barn och som anhörigtcårsare. Att förena olika roller med att vara som närstående är en svår uppgift.

Att förena yrkesarbete med att stödja eller vårda en närstående
Sarah

- Retired
- Is a carer to her husband Michael

- Has been a carer for a longer period of time
- Has a lot of knowledge
- Would like to come in contact with others in a similar situation

Is interested in the Interactive services
Hi Frida Andreasson!

What's New

Frida Andreasson Min systor har en älgpark. Bland annat har de fått tvillingkalvar och de är så söta, här är de:

1 hour ago  Like  Comment  Delete  Share
### Allmänt

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**Nyheter**

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**Litteratur, filmer, länkar**

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**Om mig själv**

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### Specifika ämnen

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**Eurocarers för ANHÖRIGA**

Kommunicera med andra

<< Tillbaka till förstasidan | Socialt nätverk | Meddelanden (3) | Chat | Video Chat | Forum

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Sök
Coping with Caregiving

Last Updated on 18/12/2014

The Caregiving years: An introduction

When you expect a child, the community (your family, friends, co-workers) rally around you and your spouse.

More>

Carers' stories

I am exhausted and extremely tired but I have not had a good night's sleep since we moved. Everyone tells me to stop worrying, things will work out, etc, etc.

More>

Looking after yourself

Being a carer sometimes makes it difficult to take care of yourself. Priorities are changing as the disease progresses and looking after yourself takes usually last place on a long list of heavy duties.

More>

Coping with stress and depression

Stress is not something you can avoid.

More>

Relaxation technique

When we are thinking of relaxation, we usually think of doing activities that involve movement.

More>

Coping with dementia

The Coping with Dementia DVD is made up originally of 3 chapters and...
Jack

- Is a working carer
- Supports his father Tim at a distance

- Has been a carer for 2 months
- In need of information
- Less need of communicating with others in a similar situation

Is interested in the information pages about Parkinson’s disease and support available to him as a carer
LAST UPDATED ON 18/12/2014

This section is devoted to Pathologies of older people and care management.

Information on a number of diseases are provided.

You may visit each page by clicking on boxes below or by clicking on your left side list.

Dementia

The term “dementia” refers to a group of symptoms that appears to people with diseases which destroy brain cells and cause a gradual deterioration of cognitive abilities.

Parkinson Disease

It is a progressive neurological disorder, which so far cannot be cured.

Stroke

A stroke is a brain attack. For your brain to function, it needs a constant blood supply, which provides vital nutrients and oxygen to the brain cells.
Parkinson’s

At its simplest, it is a progressive neurological disorder, which so far cannot be cured. It is variable in its progression. I.e., some people progress more slowly than others, and the symptoms can be effectively controlled with medication for many years. Parkinson’s results from a shortage of dopamine, a chemical that helps instructions from the brain to cross from one nerve cell to the next. In a part of the brain called the substantia nigra, which has to do with controlling movement. We all lose some of this chemical as we get older, and the loss starts at birth! However, it is only when we have lost about 80% of our dopamine we start to have symptoms. So people with Parkinson’s have lost this chemical at a slightly faster rate than others.

So how can you help yourself?

Parkinson’s does not react well to stressful situations, so avoid stress as much as possible. Eat well-balanced diets and exercise often to keep joints and muscles agile and flexible. Continue to live well and do not avoid social interactions. Drug management is critical to living well, and it is important to take any drugs prescribed to you in the way that they have been prescribed.

*progressive = getting worse over time Substantia Nigra
Are you interested in best practices for carers in your country and searching for national organisations?

If yes, you have only to visit links below!

Sharing information and knowledge is a core dimension of carers' community.

Being aware of projects, methodologies and strategies which are effective and accessible for carers in your country might offer you valuable information.

Additionally, you could also find contact details of national carers and disease – specific organisations in order for you to gain access to more information and advice on relevant topics.

- Web-based good practices
- Find your national organisation
How to support carers online
What are your thoughts about online carer support?
Different types of “channels” for online support

- Forum
- Facebook
- Twitter
- E-mail/private messages
- Chat
Different types of support

- Support from NGO’s, professionals
- Peer to peer support
- Support one to one
- Group support
- Community support
Boards.ie National chat forum with many sub groups:
- Carers and caring
- Parenting
- ASD parenting

Special Needs Active Parents (SNAP) forum

Facebook groups
- Special Needs Parents Association
- Fragile X Support Group
- Carers Who Care
- Lewy Body Dementia Carers
- National Carers Week
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Lewy Body Dementia Carers

Gå med i gruppen om du vill se diskussioner, inlägg och kommentarer.

Medlemmar (3 197)

Administratörer

- Paula
- Rice
- Biever

Sue Griffiths

Kim Leslie

Lyndsey Williams

Andra medlemmar

- Helaine
- Heiker
- Lewis

Jessie

Durham

Stacy

Herman

Arlene

Witkowski

Vicki

Hydo

Cindy

Sato

Beskrivning

This group is for anybody affected by LBD individuals family or friends,
i started this group as 6 years ago when my mother was diagnosed
i had nobody to talk to who knew exactly what i was going through
so it is to allow others to ask question about LBD experiences
and to share their experiences in the hope we can help each other
Be sure to check your "other" inbox for a message from Admin.

Gruppstyp

Support

Tags

Lewy body

Skapa nya grupper

Med Grupper blir det enklare att anlita någon som allt du med sig till vänner, släkt och arbetskamrater...
Legal and ethical aspects

• Avoid publishing offensive personal data
• Check posts regularly for offensive personal data.
• Promptly remove offensive personal data
• Inform users about what sorts of comments are not allowed and explain that they will be removed.
• Encourage users to report offensive content to the organisations, have routines how to handle complaints.
• Design the profile in the social media so that it clearly states which organisation is behind it.
Ground rules

- In the use of the social media we keep a respectful, encouraging and supportive tone.
- Members shall be able to express their thoughts about their life situation without moralization or judgments.
- We will not disclose names or personal information concerning our loved ones, staff or significant another. We do not include the specific names of institutions, i.e., nursing homes, meeting points for example.
- We do not write anything that is considered to be offensive or discriminative.
- Advertisements are not allowed.
- The posts must not violate any laws, rules, regulations or linking to such sites.
- On the forum the moderator has the opportunity at any time to move posts to a place where it fits better which makes the forum easier to follow and navigate.

Breaking the ground rules may mean that messages are deleted or that the member is excluded from the forum.

If any thread or post violates the rules report it promptly to the moderator.
How to get started (Forum)

• Privacy settings!

• You choose yourself what to write, how much or how little you want to write and share.

• Look at what others write about and how they write!

• You can use a username instead of your real name.

• You always have the possibility to edit your posts

• You are always welcome to contact the moderator about help to get started!
Moderator’s role

• Creating a safe environment, community
• See that everyone follows the rules
• ”Mirroring”
• Keep discussions going, provide new input
• Motivating
• Supporting
• Acknowledging the carers
How to provide online support

• Motivate carers to use the online support and continue using it
• Balance positive and "negative" posts
• Meet different needs; carers in different phases and situations
• Support digital skills- EXAMPLE
• Education/training/description how to use the online support
Example

Elsa is very active in the Facebook group. She is very straightforward as a person. Other carers think she writes in an offensive tone about the person she cares for. How could you act as a moderator?
The general usage

The most frequently used services: Social network, social forum and private messages

Mainly **SHARING** (tips, emotions, thoughts; negative and positive) (E-mails)

**Confirming** users’ experiences, asking questions, helping them to **reflect on their situation** (and/or referring relevant sources of literature and media)

Not so many requests for information or advice

The active users had been **caring for a longer period of time** and had already gained extensive ‘first-hand’ knowledge and experiences.
Lessons learned from the pilot study

• **Education/training** in how to use the web platform

• **”Fostering”** how to use different web-based services takes time and perseverance. (it has been challenging to motivate carers to use the services.)

• **To have a moderator** is crucial (more carers active in the evening)

• **A safe setting** with people in similar situations is appreciated

• **Caring is complex** and the variety of carers’ needs and preferences represent a challenge. (caring over an extended or shorter period of time, older or younger carers, working carer, former carers etc)

• **Positive with several different services**

• **Technical issues and usability** affects motivation

• **It is necessary to have several active members** to create an online community

• **An online community enables development of personal relationships** among carers- preventing feelings of social isolation.
Carers’ experiences of using online support
Carer’s feedback

• Flexible
• Important with learning opportunities
• Can’t replace Face to face meetings
• Peer to peer support
• Strengthening, empowering
• Acknowledgement
Some challenges

• Lack of time
• Time of year- Swedish summer time!
• Computer skills
• Insufficient computer training opportunities
• The caring situation
• Technical issues and usability
• Too few participants
• (internet connection)
Impacts

Personal situation
• Acknowledgement *
• Meeting others in a similar situation
• Hope and strength

Impact on the cared for person
The carers’ wellbeing affects the cared for person’s well-being *

I have felt that my experiences are worth something, that I ’m not simply an old lady in my 70’s that should just sit and be quiet”

“I feel less stressed and that can be a result of other people’s posts, that now I can allow myself to have negative feelings and thoughts”.
“I met Eric when I was in a project about care for older people. I was caring for my husband who was ill and Eric was caring for his father. We were communicating via chat, mostly about how the municipalities helped us in our situations as carers at that time.

Now, a year afterwards, Eric has lost his father and I have lost my husband. /--/The grief is heavy for us both. Eric has been a support to me and has, with his computer skills, helped me so much. Already last year he explained a lot of things to me that I didn´t understand. Now it has really helped me. Eric has helped me learn how to blog. I’ve found a new interest.”

Annie, 73 years, a former carer
Would it be possible for your organisation to offer online support?

- What challenges can you see?
- What benefits can you see?
Thank you!

Frida Andréasson
Frida.andreasson@anhoriga.se

http://eurocarers.org/informcare/