

”Who helps those who help?”

This report is part of NSPH’s work in shedding light on and improving the situation for family carers in the member organizations.

When we use the term family carer we mean people within the family, relatives and other people such as friends, neighbours etc., who have a relationship to a person with mental ill health who they care for. The aim of the questionnaire was to gain a clearer picture of the family carers’ situation and investigate what needs, experiences and wishes they have in order to be able to improve and facilitate their lives.

Do you want to know more about our work? Contact us at NSPH’s office. E-post: info@nsph.se or call: 08-120 488 00



TABLE OF CONTENTS

Thank you!.....	4
BACKGROUND.....	5
SUMMARY.....	6
RESULTS OF THE STUDY.....	6
Figure 1. Diagnosis (several responses could be given).....	7
Figure 2. Do you yourself need support in the form of advice, information and relief?.....	7
Figure 3. Have you or anyone else in your family received information about what the health services and social services can offer in terms of support for family carers?.....	8
Figure 4. Have you or any other family member sought or been offered support in their role as a family carer?.....	9
Figure 5. If yes, which of the following services have you received?.....	9
Figure 6. Are you satisfied with these services?.....	10
Figure 7. Do you feel that the staff in the health and social care services or the staff at other authorities that you have contact with have knowledge and an understanding about your situation as a family carer?.....	11
Figure 8. Have the relationships in your family been affected by the cared for person's mental ill health?.....	11
Figure 9. If you work, is your work affected by situations that occur when the person you care for is ill? Several answers can be given.....	12
Figure 10. Do you feel that there is any understanding for your situation at home at your workplace?.....	13
Figure 11. Have you been on sick leave due to your role as a family carer?	13
Figure 12. Does the person you care for have a financial situation so that he/she can manage his/her costs of living?.....	14
Figure 13. Do you feel worried about the health of the person you care for?.....	14
Figure 14. If you could have your wish, how would you want the support for you as a family carer be organized?.....	15
NEED FOR SERVICES.....	16
NSPH's MEMBER ORGANIZATIONS.....	17

Thank you!

We would like to give a huge and sincere thanks to all those of you who have taken your time to answer. NSPH see your answers as a significant contribution to increased knowledge about the situation for family carers and your answers are an important part of the work we will continue to do to influence the health authorities and social services in the country to further develop their services.

BACKGROUND

The Swedish Partnership for Mental Health is a network of organizations for patients, users and relatives within the psychiatric field. The network has, since its start in 2007, worked for the development of psychiatric care and support for patients, users and relatives. A working group was formed within the network in 2012 with a specific remit to gain greater knowledge about issues concerning family carers both internally and externally and to contribute to the improvement of support to them.

The network has, through this internal working group, created a platform for the work on issues concerning family carers and a booklet for a family carer of someone with mental ill health. Both these documents have been received with great interest by organizations as well as by the health services and social care services. Family carers have particularly appreciated the suggestions and advice that NSPH has provided. The working group has also taken the initiative for the project Anhörigprojektet - The Family Carer Projekt - that existed 2014-2017 with financial support from the State Inheritance Fund.

The aims of The Family Carer Project was:

- The family carers who participate in the project's study groups will be better equipped in their contacts with the health care and social care services, have easier access to information and be involved in the care, while at the same time still being a relative and not a carer.
- Compile and communicate knowledge about how relatives can be better at taking care of themselves.
- Compile material that describes routines and ways authorities can work that include relatives, improves the support to them and takes their need of information into consideration in spite of the demands for confidentiality.
- Compile material for study groups that is specifically aimed for the target group.
- Create places for and channels of communication between NSPH's member organizations and health care services and social services' family carer counsellors that in the long term can contribute to an improved support for relatives.

Furthermore the staff, who participate in the project, should be better at supporting and including family carers of people with mental ill health and at giving them information.

The project focuses on family carers of adults with mental ill health. The results that are presented in this report are from a questionnaire that was designed for the project in order to gain a clearer picture of the needs, wishes and experiences of support to family carers in order to be able to contribute to improving and facilitating for them.

The project was run by The Swedish Schizophrenia Fellowship in cooperation with NSPH 2014-2017.

SUMMARY

The results from the responses to the questionnaire show that many family carers have a difficult situation. The responses largely confirmed many of the experiences that NSPH and its member organizations have. A great majority of those who answered did it as mothers (62%). Fathers were in fifth place (6%). This difference is remarkable and should be further investigated. Other important details from the responses to the questionnaire:

- A great majority (74%) answered that they themselves needed support because of their situation as a relative.
- Most had not received any information about what the local authority or the health authority offered in the form of support for family carers. Only 6% reported that they had received very good information about this and 37% stated that they had received some information.
- Only 41% had applied for or been offered some form of support for family carers. The most common service they had received was education for relatives, meetings with others for sharing experiences (40%) and psychosocial support (39%).
- Unfortunately the answers to an open follow-up question about how satisfied one was with the services showed that these were often inadequate or badly suited to their needs.
- In the response to the question about whether the staff they met in the health care services, social care services and other authorities had knowledge about the situation for relatives, only 3% gave an unequivocal yes, 32% answered no and 12% did not have such contacts. 53% stated that there was sometimes or often knowledge about the relatives' situation.
- Family relationships are noticeably affected if someone in the family suffers from mental ill health. 51% report that it has led to great friction and tension or separation. 32% have answered that they have been able to adjust to the situation, 11% think that the relationships have been strengthened and 4% say that they have not changed.
- Work is noticeably affected by being a relative. All of those who work report that they have reduced their working hours, changed jobs or have needed to leave work to give support in contacts with the health services and authorities or in a crisis. 48% have been off sick. In spite of this a majority make regular financial contributions to the cost of living of the cared for person.
- Almost all (98%) experience worry due to the health situation of the person they care for.

It was clear from the answers to the questionnaire that the need for support for family carers was great. Many stated a desire for psychosocial support, relief, help in coordinating contacts with the health services and authorities, support in everyday life and help with financial issues. Last and not least many expressed a great need for education and meetings for family carers.

We have seen in our work that relatives can and want to help, but this study shows that the cost of this is often very high and that society's help to those who help their family members has great deficiencies. We describe in the final chapter what NSPH thinks should be done.

RESULTS OF THE STUDY

A total of 1393 people have completed the questionnaire. More than 6 of 10 responders were mothers (62%). The next most common was partners (13%). The proportion of siblings was 7%.

The number of fathers who answered was remarkably small (6%) as for grandparents (1%). Child was the most common alternative among “others”.

Figure 1. Diagnosis (several responses could be given)

Relatives to a person with a neuropsychiatric disability were the most common (70%). Followed by depression/anxiety (29%), bipolar disorder (13%) and psychosis (11%), see figure below.

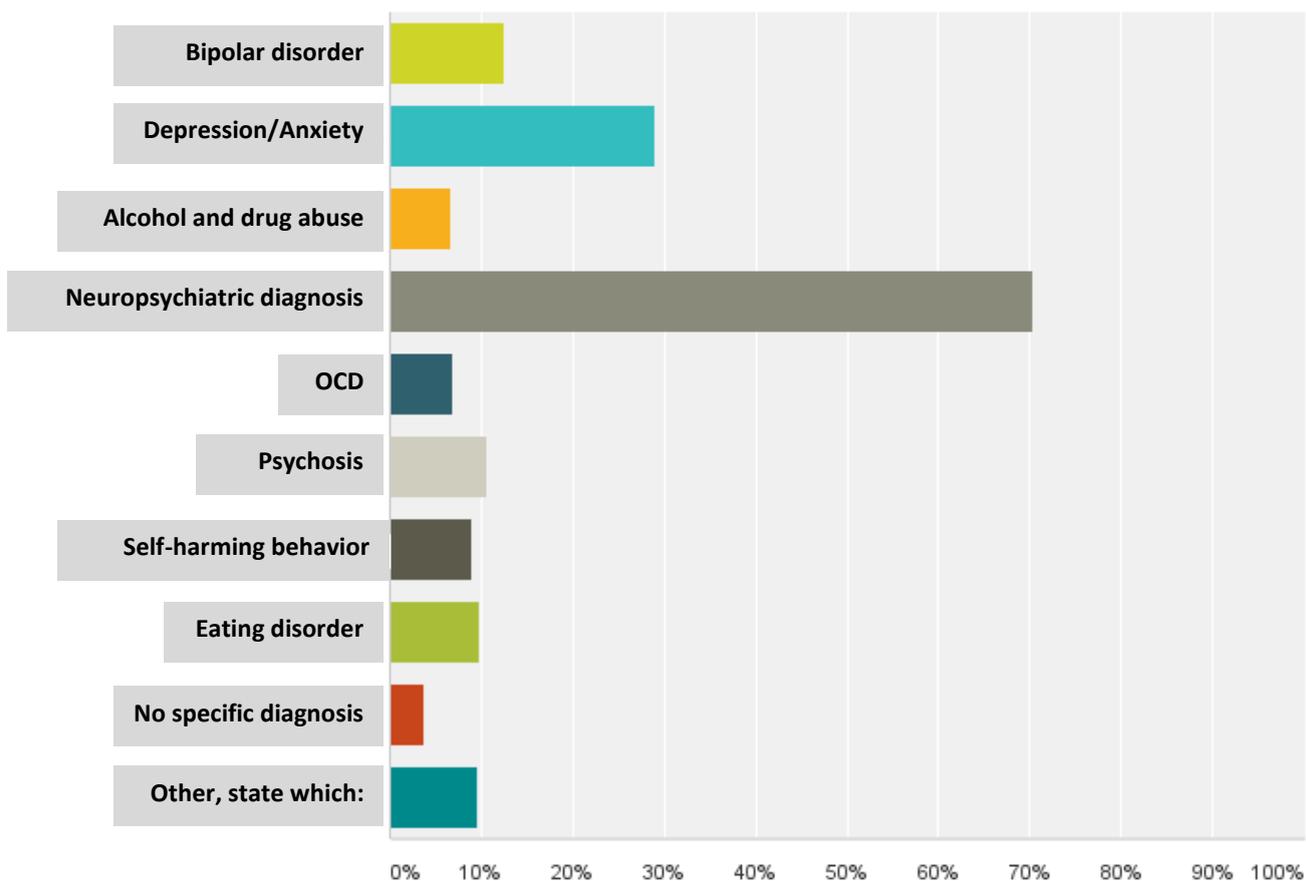


Figure 2. Do you yourself need support in the form of advice, information and relief?

The proportion, who answer yes to this question, is very high (74%). Only 19% think that they do not need any. A majority (62%) know that they have the right to receive support for themselves but 38% do not know this.

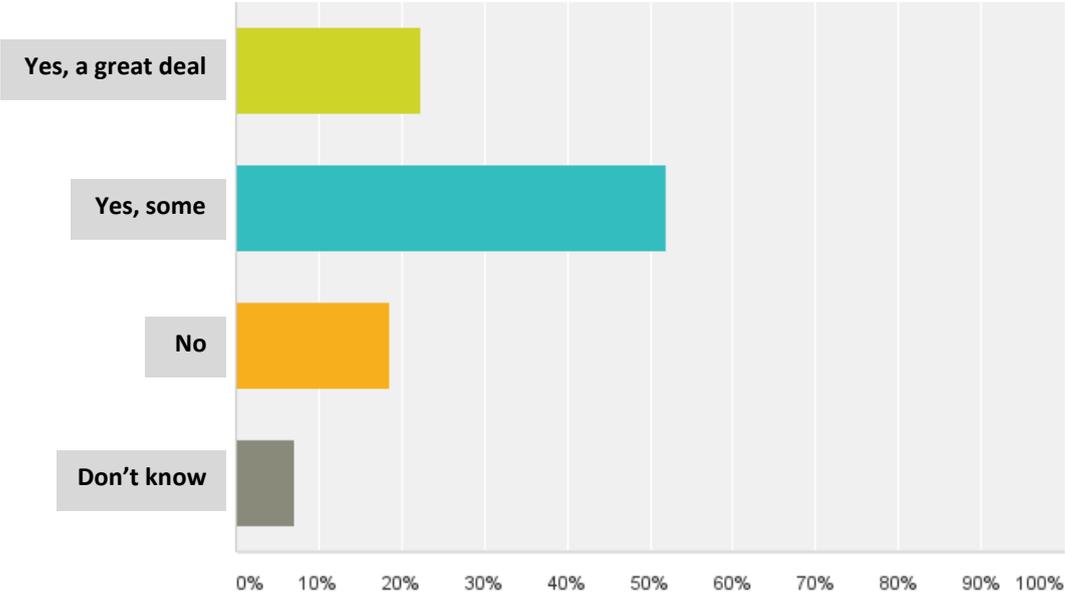


Figure 3. Have you or anyone else in your family received information about what the health services and social services can offer in terms of support for family carers?

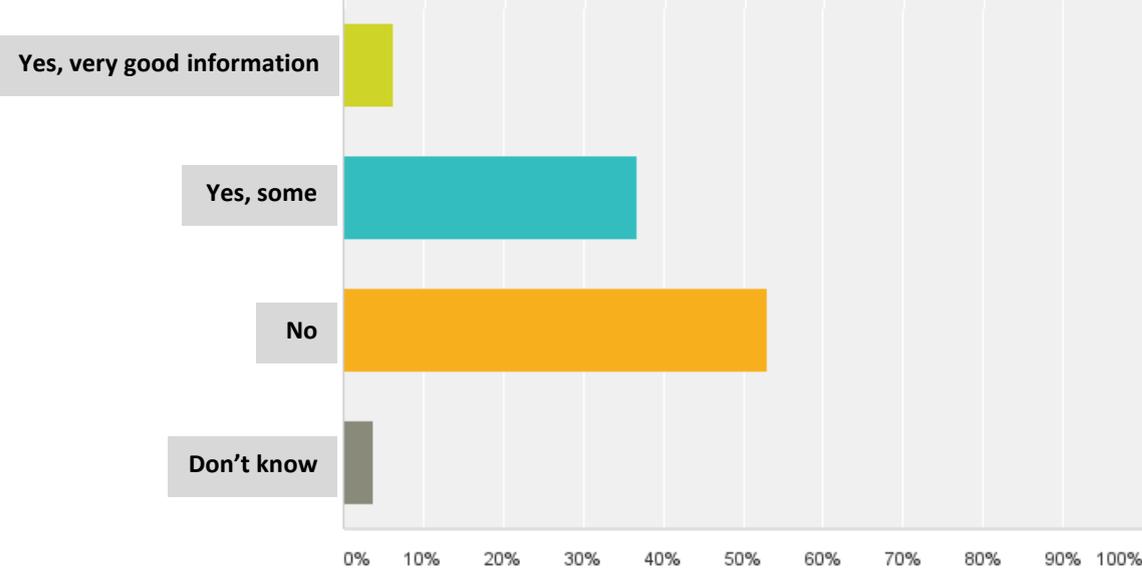


Figure 4. Have you or any other family member sought or been offered support in their role as a family carer?

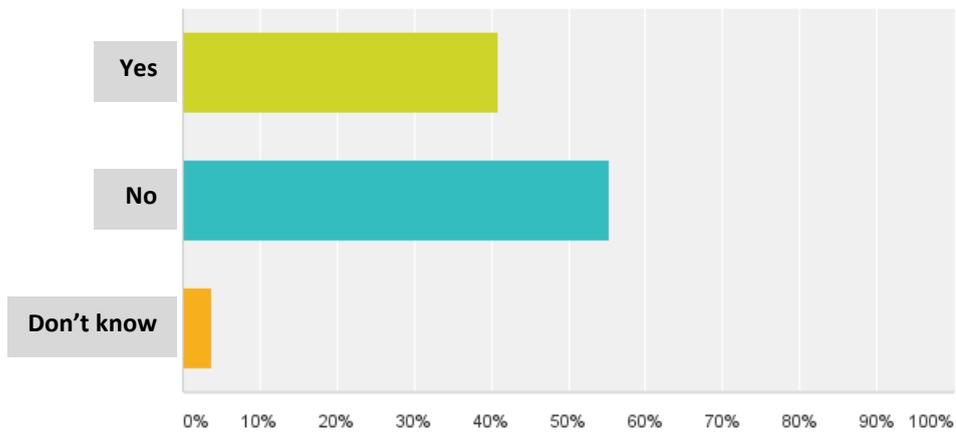


Figure 5. If yes, which of the following services have you received?

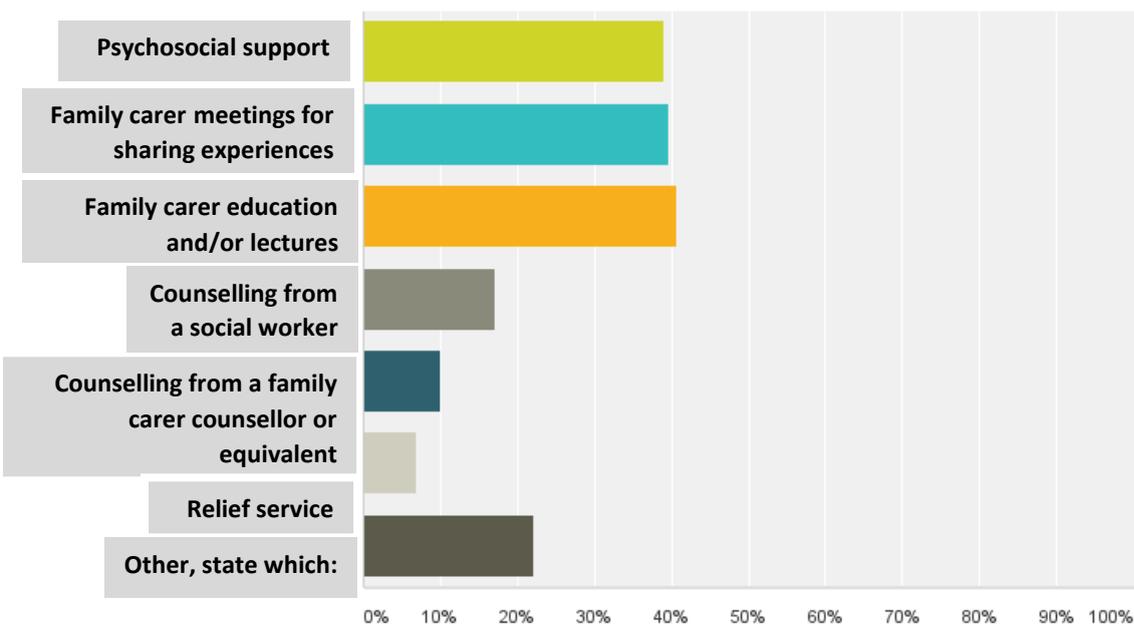
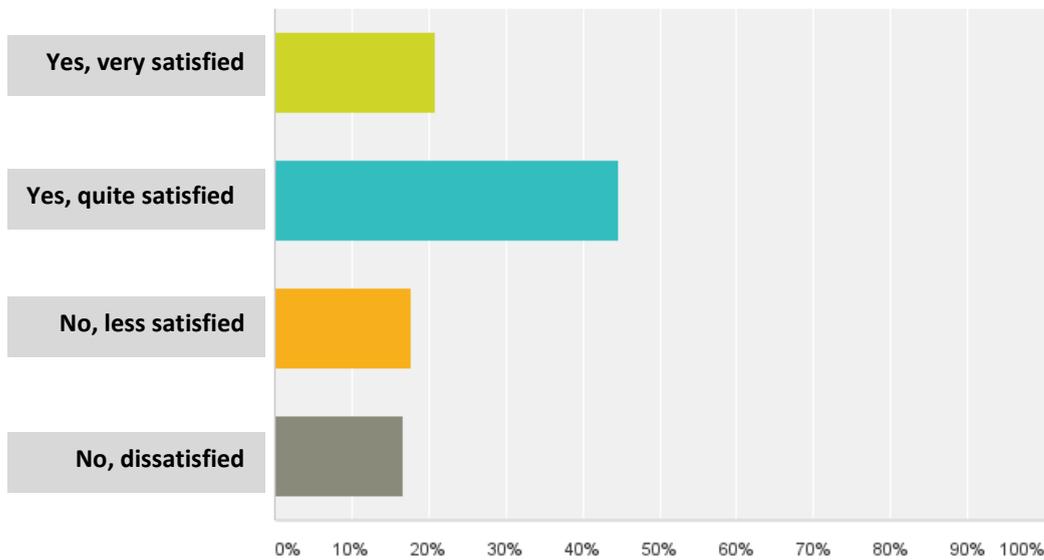


Figure 6. Are you satisfied with these services?



Comments could be added as a follow-up to this question, only 30 of these were positive and 120 were generally or very dissatisfied. The dissatisfaction concerned both attitudes they had met and the level of support.

Comments:

The services provided by the municipal social services have been inadequate. Combining the Act concerning Support and Service for Persons with Certain Disabilities and the Social Services Act. No information referring to confidentiality. No report, not even to the trustee. Completely dreadful attitude. Misusing the Act concerning Support and Service for Persons with Certain Disabilities and using the user's easily influenced view on the reasons for these services. No reports at all. Really dissatisfied.

Should need help with cleaning at our son's home, but he doesn't let anyone else clean. I'm 69 and have a wheelchair, my husband is 74 and he tries to help our son with the cleaning as much as he can. We can hardly manage to clean our own place so it's a big problem.

Have had to struggle for many years before anyone even listened properly.

Was questioned as a relative. Got the question "why are you together with a person who has such a serious mental disorder, you could have a better life than this"... The idea according to the staff was to put my thoughts into words. The matter is that I've never even thought that at all. You see the person and not the diagnosis. It still makes me angry today and that was five years ago.

As long as the person I care for lives in misery then the support for me doesn't make any real difference.

Unfortunately relatives are sometimes experienced as being difficult because of a great need to talk. The health care services have never taken an initiative to talk. It's always us the relatives, who have taken the initiative to have a meeting.

Figure 7. Do you feel that the staff in the health and social care services or the staff at other authorities that you have contact with have knowledge and an understanding about your situation as a family carer?

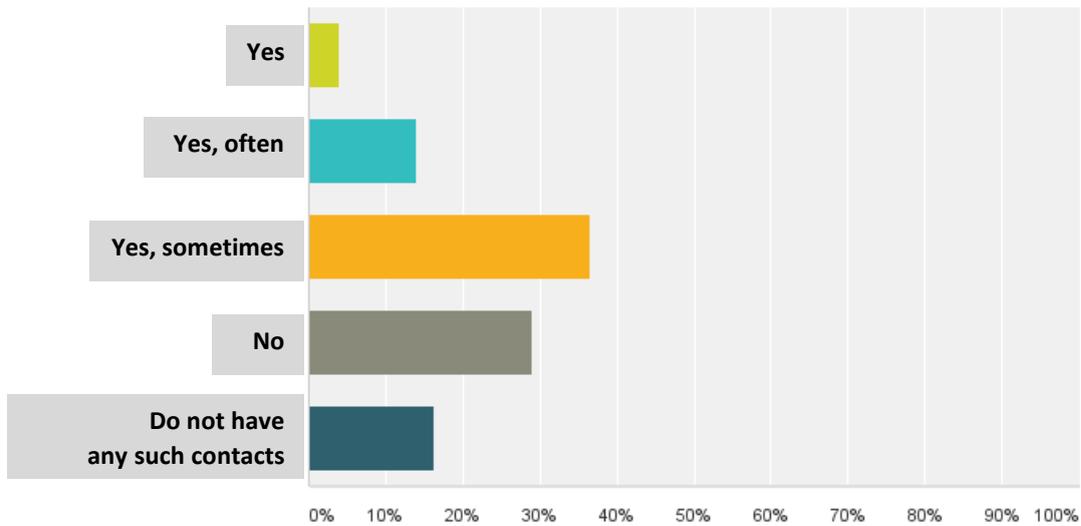
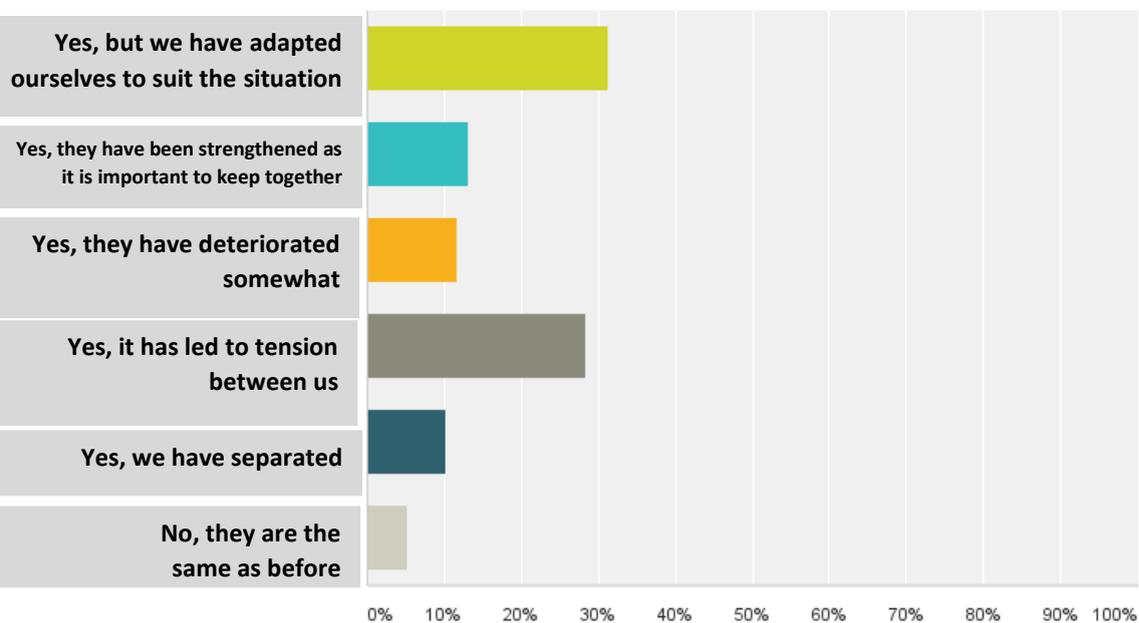
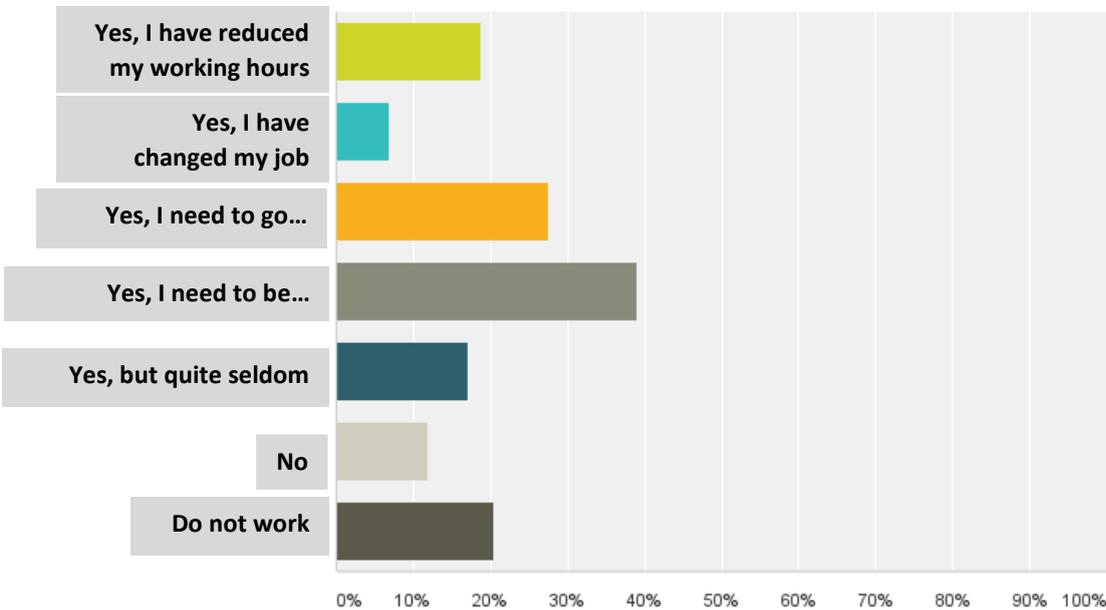


Figure 8. Have the relationships in your family been affected by the cared for person's mental ill health?



**Figure 9. If you work, is your work affected by situations that occur when the person you care for is ill?
Several answers can be given.**



219 people have written comments in conjunction with answering “Yes, it affects”. 11 have written comments in conjunction with answering, “No, it has not affected”. 52 people have commented in conjunction with answering “Yes, it affects in some way”.

Examples of comments from those who have stated that their work has been affected:

Have changed my working hours over the years and taken time off on several occasions to go to meetings etc. It has felt at times that it's a full-time job just to help my son.

It's difficult to concentrate on my work during the worst periods that's why I've reduced my working hours.

Have several times had to leave work early when the anxiety attacks have come and have to always accompany him for the appointments at the psychiatry unit and be there all the time.

Have had a disability pension due to the extreme strain of working and taking care of a child with a disability.

Should really need to reduce my working hours in order to get everything in the work-life balance to function but I can't afford it despite having a ¼ of a care allowance but it doesn't cover my income loss. Can't really manage everything that needs to be done to support my child and don't have time to rest myself.

Figure 10. Do you feel that there is any understanding for your situation at home at your workplace?

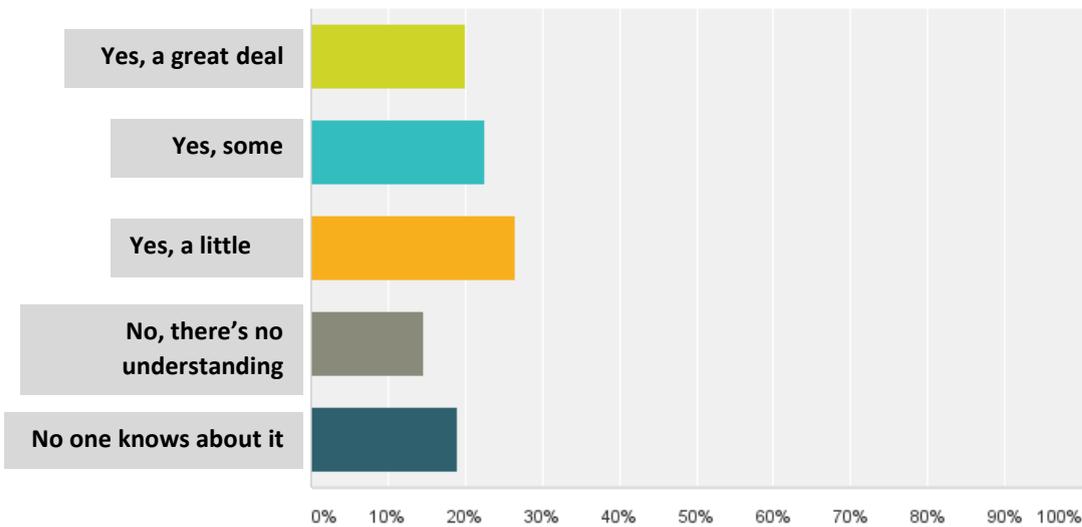
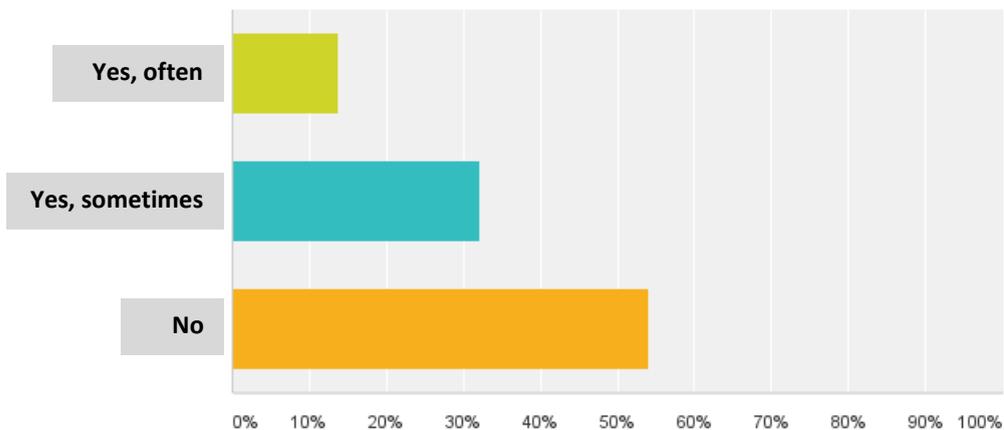


Figure 11. Have you been on sick leave due to your role as a family carer?



Examples of comments from people who have answered Yes (155):

I've been off sick for exhaustion and depression during two consecutive periods when far too many difficult things happened that demanded so much of me at all levels simultaneously. This has led to a situation when things have been sorted out for the cared for person that I'm so exhausted so nothing works.

Off-sick full-time for long periods! Not easy to come back!

Have suffered from exhaustion and depression. Take part in a counselling group at the Stress clinic. Have discovered that 2/3 of the participants have children with ADHD or something similar.

Had two long-term periods of being off sick. Was burned out.

Examples of comments from people who have answered No (67):

Have my own company and have thus not been off sick but have adapted my work around the situation.

Have taken time off on occasions after my holiday. Have even tried to get time off a morning or an evening in order to be able to accompany him to an appointment at the psychiatry clinic.

Figure 12. Does the person you care for have a financial situation so that he/she can manage his/her costs of living?

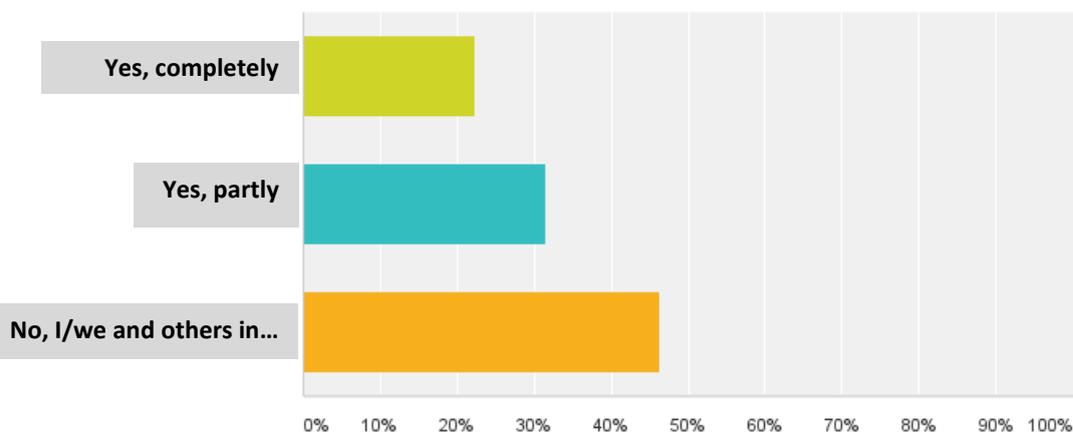
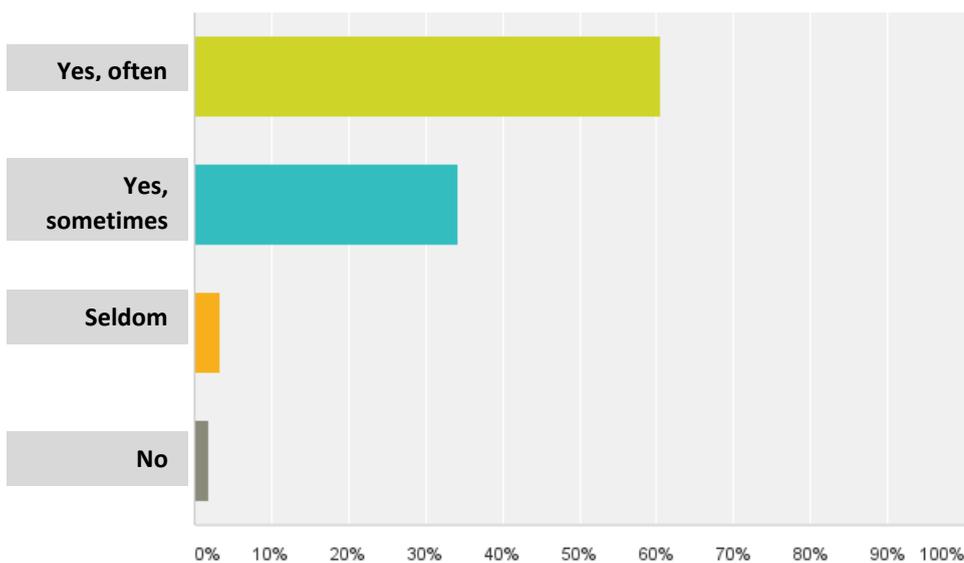


Figure 13. Do you feel worried about the health of the person you care for?



When we asked if they had anyone to talk to, 18% answered Yes, one or more, 49% answered Yes a couple, 20% answered Yes, one and 13% did not have anyone to talk to.

Figure 14. If you could have your wish, how would you want the support for you as a family carer be organized?

We received 928 answers to this question which generated a large material and an important source of knowledge. The answers demonstrate that relatives to people with mental ill health often have a very difficult time and provide a great many services, but seldom receive the support they need. Several point out that the support provided by the municipalities is mainly intended for the elderly.

An analysis of the answers shows that it is the following services that are mostly wanted:

Desired service	No. of responses
Psychosocial support/contact person	212
Relief/compensation	104
Coordination	99
Adapted help	88
Education/material/knowledge	81
Family carer meetings/groups	62
Confidentiality/participation	35
Easily accessible information	18
Other services	157

In one comment it was stated that *“We’ve been lucky and have got all the support we could possibly have needed and need “*. If anything then this quotation is quite remarkable as it should really be the opposite, where one is unlucky when one does not receive sufficient support or support that is not adapted to the situation in question. Very many just wanted such simple things as someone from the health services taking time to just listen to them or that one got the information that there actually was some tangible support to get.

There were many graphic comments, and a selection of these is presented below:

My son took his own life and we have not received any help afterwards either.

There should have been a “coordinator” who I could have turned to, not needing to find out everything myself, who could see the whole picture around him so that all those involved had worked with the same aims. I should also have needed psychosocial support as a parent. He’s 34 now and has other types of problems than when he grew up but my worry and concerns for him will, however, never disappear He’s my son....

I wish that they had asked me if I needed support. Asked me how I was coping with and experiencing the situation. I live together with this person and am the one who knows what everyday life is like. But no one asked.

That there is someone with time to listen

Self-help groups where I was able to meet others in the same situation where the leader was knowledgeable about the current situation and what the future could look like.

The first thing is that one gets to know that there is help that is available.

Information, information and information again about everything that concerns the diagnosis the sick person has.

More lectures about the relatives' situation. Information about what the illness entails and how I as a relative can best help the one who is ill.

That there is a way in that can accommodate and adapt the support to my situation. I am over-stretched and should not suffer because the municipality/ county health services/ other authorities are not able to cooperate.

Greater openness and understanding, information from the professionals. Communication needs to be improved so that they don't hide behind confidentiality.

What will happen when I've gone?

It's really a case of wanting one's relative who's ill to get the help that he/she needs so that one doesn't need to feel bad because he/she feels bad. If he/she gets help then I'll be helped as well.

NEED FOR SERVICES

This study confirms the need for specific support for family carers of people with mental ill health. The demands that we have previously made of authorities, health services and decision-makers remain:

- Relatives have the right to be treated well and respectfully
- Knowledge about the disability/illness for both the relatives and the cared for person
- Good treatment that is started in time is the best help, then relatives do not need to take responsibility for the care
- Confidentiality should be able to be discussed
- Support is a right that is to be provided, one should not have to try and get it oneself
- The services should be flexible and individually adapted
- Having one's own support and a possibility to work through the situation is important for one's health – far too many become ill themselves
- Particular attention should be paid to the difficulty of combining being a family carer and working

NSPH's MEMBER ORGANIZATIONS

Swedish Partnership for Mental Health, NSPH, is made up of a network of organizations for patients, users and relatives within the psychiatric field. Our aim is for our members to be able to have greater influence on the decisions that are made within this field.

Do you want to know more? Feel free to make contact with any of the member organizations within NSPH:

Healthy & Free – eating disorder charity, www.friskfri.se

The Swedish National Association Attention, www.attention-riks.se

Swedish national association for people with depression, bipolar disorder and their related, www.balansriks.se

The Swedish Association for Support to Pharmaceutical and Drug Users, www.rfhl.se

The Swedish National Association for Social and Mental Health, www.rsmh.se

The Swedish National Association for Young People for Social Health, www.rus-riks.se

Swedish Schizophrenia Fellowship, www.schizofreniforbundet.se

HOPE, www.spes.se

Swedish OCD Association, www.ocdforbundet.se

Swedish Clubhouse Coalition, www.sverigesfontanhus.se

Anxiety Disorders Association of Sweden, www.angest.se

The National Swedish Parents Anti-Narcotics Association, www.fmn.se

Suicide Zero, www.suicidezero.se

SHEDO – Self-harm and eating disorders organization, www.shedo.se

