

CARING FOR CARERS SURVEY (C4C) MALTA

Experiences of family caregivers for persons with severe mental illness: **an international exploration**



CARERS MATTER

The shift in mental health policies away from hospital-based care **makes family caregivers essential in helping people with severe mental health problems** to live in the community, but the role is often challenging **and has a huge impact on the caregiver's own life.**

CANADA 106

Results are based on **1,111 respondents** providing evidence of the continuing burden of caring for those living with severe mental illness and highlighting the contribution that carers make and the overwhelming impact this has on their own lives

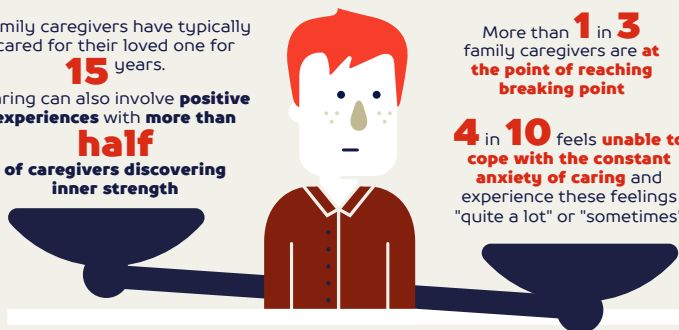


1. The highs and lows of caring

Family caregiving for people with severe mental illness involves feelings of stigma and burden; however, these experiences can be coupled with positive caregiving experiences

Family caregivers have typically cared for their loved one for **15** years.

Caring can also involve positive experiences with **more than half** of caregivers discovering inner strength



More than **1 in 3** family caregivers are at the point of reaching breaking point
4 in 10 feels unable to cope with the constant anxiety of caring and experience these feelings "quite a lot" or "sometimes"

1/3 feels that the caring role makes their own physical health worse

Nearly **4 in 10** are concerned about their own physical health

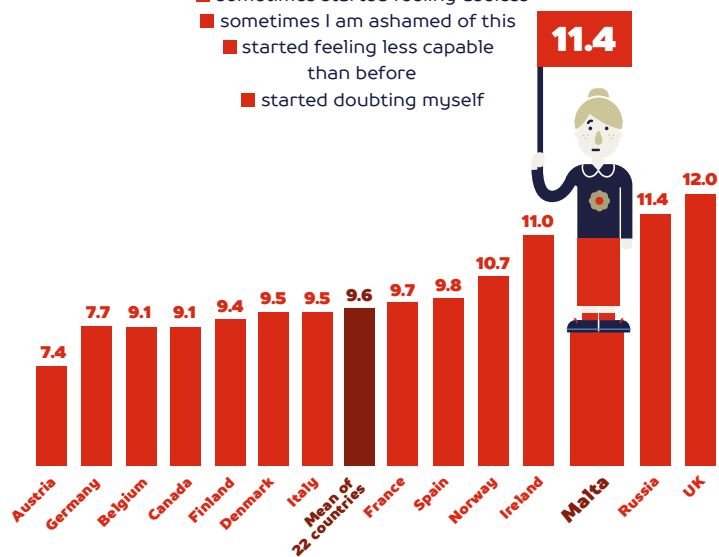


Perceived stigma of family caregivers because they got in contact with professional help*.

Malta ranks third highest, internationally:

*Mean scores on the perceived stigma scale, which consists of the following:

- started to feel inferior
- sometimes started feeling useless
- sometimes I am ashamed of this
- started feeling less capable than before
- started doubting myself





2. The real-life carer in Malta

The typical family caregiver for a person with severe mental illness in Malta is a woman, **50 years old**, caring for her child with schizophrenia



For an average of **14 years**, in line with the international average of 15 years

Spending an average of **28 hours** each week caregiving, higher than the international average of 22 hours



The majority of family caregivers in Malta who took part in the survey **live with the patient** or **live with them some of the time**. However, the report reveals that living with the patient or not **does not necessarily reduce the burden** of the caregiving role.

3. Carer support is lacking and their voice often unheard

Carers were **equally satisfied and dissatisfied** with the support from healthcare professionals, nevertheless:

4 in 10 are dissatisfied with support from doctors

A **1/3** are dissatisfied with support from nurses

And only **3 in 10** were satisfied with support from their social workers

Half are dissatisfied with the ability to seek help and support from professional staff for their own needs

1 in 4 is dissatisfied with the support they receive from their workplace

Carers were most satisfied with support from patient/caregiver organisations with **6 out of 10** feeling very satisfied

Caregivers don't feel involved in important decisions

Only **1/3** feel satisfied with their involvement in important decisions in treatment and care planning

Less than **4 in 10** carers feel that medical and care staff take them seriously

4 in 10 are dissatisfied with their involvement and ability to influence important decisions

Fewer than **1 in 4** feel communication between healthcare professionals is going well



4. Critical support for caregivers – what they are telling us they need

A **staggering 93%** would appreciate some additional support in their role as a caregiver

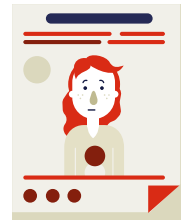
With nearly **half** requesting a significant amount of additional support



Only **7%** need no additional support

Further essential information is critical

1/3 of family caregivers are dissatisfied with the information on who to contact in case of an emergency



Almost **half** of the family caregivers are dissatisfied with information on how the illness of their relative will develop in the longer-term

Around **9 in 10** want more opportunities to meet and share knowledge and experiences with:



Professional carers **93%**

As well as with other family members and informal carers **90%**

8 out of 10 want individual support from **EUFAMI** and family member organisations by providing/offering:



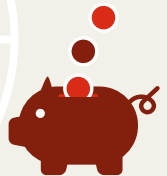
Information **88%**



Emotional support **83%**



Respite care **78%**



Financial support **62%**

About the C4C Survey

The C4C is an international survey conducted by LUCAS, the Centre for Care Research and Consultancy of the KU Leuven in collaboration with the European Federation of Families of People with Mental Illness (EUFAMI). The aim of the survey was to assess the experiences of family caregivers in caring for their relative with severe mental illness from an international perspective, and to highlight the central role they play. Respondents were recruited mainly through family caregiver organisations in the following countries: Australia, Austria, Belgium, Canada, Cyprus, Denmark, Finland, France, Germany, Greece, Ireland, Israel, Italy, Malta, Netherlands, Norway, Portugal, Russia, Spain, Sweden, Switzerland and UK. Therefore, the results cannot be generalised for all family caregivers of people with severe mental illness.

1,111 family carers were surveyed:

- 64% care for people with schizophrenia/psychosis
- 18% care for people with bipolar affective disorder
- 15% care for people with depressive disorder
- 13% care for people with anxiety disorder
- 18% care for people with other disorders

At least 26 million people worldwide are affected by Schizophrenia and it is one of the ten leading causes of disability worldwide.

EUFAMI received an unrestricted educational grant from Lundbeck and Otsuka for the survey.

Reference: Vermeulen, B., Lauwers, H., Spruytte, N., Van Audenhove, C., Magro, C., Saunders J. & Jones, K. (2015): Experiences of family caregivers for persons with severe mental illness: an international exploration. LUCAS KU Leuven/EUFAMI.