More than 1 in 3 family caregivers are at the point of reaching breaking point.

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.

With feelings of isolation and loneliness making this worse, together with the responsibility of caring and the financial stress:
- 1 in 3 feels isolated and lonely because of the situation they are in.
- 55% worries most about the person becoming too dependent on them in future.
- 1 in 2 worries about the financial situation of the person in their care.
- One in four is having difficulty making ends meet.

The worry and stress means that:
- 1/3 lack sleep because of the worry or stress.
- 1/3 feel depressed.
- 1 in 5 is unable to see anything positive in their life.
- 1 in 5 feel so exhausted that they cannot function properly.

Caring can often have a detrimental impact on the caregivers’ own health:
- 1/3 feels that the caring role makes their own physical health worse.
- Nearly 4 in 10 are concerned about their own physical health.

Join the conversation online and help create awareness about the impact of caring for people with mental illness.

www.caringformentalhealth.org #C4CSurvey

twitter/EUFAMI facebook.com/EUFAM11
2. The real-life carer

The typical family caregiver for a person with severe mental illness is female (80%) and around 60 years old, with

- 76% taking care of a son or daughter
- 10% for a partner or spouse
- 7% for a brother or sister

Spending an average of 22 hours each week caring.

3. Carer support is lacking and their voice often unheard

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

- 4 in 10 are dissatisfied with support from doctors
- 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
- Only 3 in 10 were satisfied with support from their social workers
- Caregivers were most satisfied with support from patient/carer organisations with 6 out of 10 feeling very satisfied.

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

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%

4 in 10 are dissatisfied 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.

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.

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.

Caregivers don’t feel involved in important decisions

- Only 1/3 are satisfied with their involvement in important decisions
- 4 in 10 were dissatisfied with their involvement and ability to influence important decisions
- Caregivers were most satisfied with support from patient/carer organisations with 6 out of 10 feeling very satisfied.

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.

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.

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