



# Caring for Carers Survey [C4C]<sup>i</sup> Experiences of carers of persons with schizophrenia

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## 1. The aim of the C4C Survey

*The majority of (family) carers live with the illness 24 hours of the day, each day of the year<sup>ii</sup>.  
Meeting the expressed needs of family caregivers will quicken the recovery of their loved ones.<sup>iii</sup>*

The C4C Survey is an international survey being undertaken by the European Federation of Associations of Families of People with Mental Illness [EUFAMI], in collaboration with LUCAS, center for care research and consultancy of the University of Leuven, to understand the needs and challenges faced by carers supporting those living with a mental health illness. The survey, the first of its kind<sup>iv</sup>, is being conducted in 25 countries in total\*, mainly in the EU and will close by the end of 2014.

Initial results, released on 10<sup>th</sup> October 2014, highlight findings from Australia, Canada, France, Germany, Italy, Spain and the UK. The survey (covering more than 400 people caring for relatives with severe mental illness, in particular schizophrenia) was conducted to understand the needs and challenges of carers.

There is already a general recognition that carers' needs are closely linked with those of the person they care for, however this survey was designed specifically to find out about the circumstances and burdens of carers themselves.

EUFAMI believes that the findings should be of considerable benefit to many organisations and to policy makers, as well as to EUFAMI's member associations, to inform discussions about priorities for future actions to support these carers.

\*Countries surveyed: AUSTRALIA, AUSTRIA, BELGIUM, CANADA, CYPRUS, CZECH REP., DENMARK, FINLAND, FRANCE, GERMANY, GREECE, IRELAND, ISRAEL, ITALY, LITHUANIA, MALTA, NETHERLANDS, NORWAY, PORTUGAL, RUSSIA, SLOVENIA, SPAIN, SWEDEN, SWITZERLAND & UK

## 2. Why the Carer?

### **EUFAMI:**

***Carers for people affected by schizophrenia often feel undervalued. During early psychosis, interventions aimed at the family can facilitate patient identification, improve the emotional well-being of family members and support carers in their unquestionably important role in promoting remission and recovery<sup>v</sup>.***

Community-based care and prevention is now preferred over long-term hospitalisation for people with mental health conditions, and the responsibility for care has shifted from hospitals to informal carers, such as a relative<sup>vi</sup>.

Family carers are in a position to intervene early before the symptoms of a potential episode worsen, the situation escalates and the person with schizophrenia needs to be hospitalised<sup>vii</sup>. Early intervention means providing information, assessment and treatment at the earliest possible time when the person with schizophrenia starts experiencing psychotic symptoms, and the complications that can arise from untreated psychosis take hold<sup>viii</sup>.

Carers fulfil a distinct and important role by providing support and advocating for their ill relatives as well as contributing to their recovery<sup>ix</sup>.

The relapse rate at 2 years was 40% in patients whose families received psychotherapeutic support, compared with 75% in those whose families received no help<sup>x</sup>.

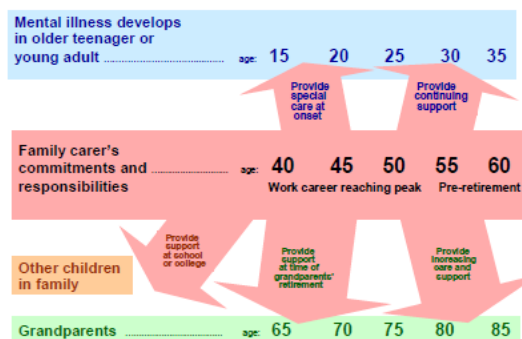
Caring for someone with schizophrenia takes time, energy, financial and emotional resources<sup>xi</sup>.

In 2012, the estimated total cost of psychotic disorders such as schizophrenia in Europe (the 27 members of the EU, plus Iceland, Norway, and Switzerland) amounted to €29.0 billion—equivalent to €5805 per patient per year<sup>xii</sup>.

Despite the essential role that family carers perform, they are not fully recognized as crucial partners in care so far. Although caregiving may give rise to positive feelings and experiences, carers feel highly exposed and caring for a relative with mental illness is related to high personal suffering, feelings of guilt, helplessness, fear, vulnerability, anxiety and anger<sup>xiii</sup>.

When a mental illness “enters” the family circle, family members tend to remove themselves from their natural support networks for a number of different reasons<sup>xiv</sup>. Additionally, at the age of onset of a child’s mental illness, the age of family carers (40–60 years) and the possibility of separation or divorce mean that they are at a time of great family stress and pressure (figure 1)  
<sup>xv</sup>.

Figure 1



### Family member account:

*"... my son, Thomas. He is now 40 years old and has been suffering from schizophrenia for 15 years. Even today I am still trying to cope with the effects that his mental illness has had on me."<sup>xvi</sup>*

Given that the frequency and intensity of psychotic episodes is unpredictable in those with schizophrenia, coping with such a condition poses ongoing challenges to family carers<sup>xvii</sup>.

### 3. C4C Survey - Study design

The purpose of the survey is to capture and document the experiences and well-being of family caregivers of persons living with schizophrenia, giving us more insight into the caregiver's role in mental disease management.

Supported by an educational grant from the leading CNS alliance, Lundbeck and Otsuka, the survey has been developed by EUFAMI in collaboration with LUCAS, the interdisciplinary centre for care research and consultancy of the University of Leuven.

The survey follows an exploratory study design, with no predefined hypothesis and the topics addressed are:

- Well-being
- Need for support
- Satisfaction with professional support
- Socio-demographic and illness related characteristics

In addition to these topics, the questionnaire also gleans information on the basic profile of carers, their experiences, and financial, emotional and physical burdens.

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Date of preparation: October 2014

The questionnaires are disseminated through EUFAMI's member organizations in 25 countries and administered on paper, by email or online. The survey is still open, and is expected to run until end 2014.

### **About European Federation of Associations of Families of People with Mental Illness [EUFAMI]**

The European Federation of Families of People with Mental Illness (EUFAMI) is a European non-profit organisation registered in Belgium that primarily advocates on behalf of families and family carers. EUFAMI is recognised as the 'credible voice' of families and carers in Europe. It was founded in 1992 and represents 41 family member associations in 22 European countries and one non-European country. For further information please visit: [www.eufami.org](http://www.eufami.org).

### **About KU Leuven LUCAS**

**LUCAS** is an interdisciplinary research centre of the Belgian university **KU Leuven**, active in the fields of care and welfare. Their mission is threefold: research, training, and consultancy. In all three areas, they bring together insights from policy, practice and research, and this in constant dialogue with all stakeholders. [www.kuleuven.be/lucas](http://www.kuleuven.be/lucas).

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<sup>i</sup> C4C Survey, LUCAS Centre for Care research, September 2014

<sup>ii</sup> Hogman G. et al. *EUFAMI survey into carer needs*. Leuven, European Federation of Associations of Families of People with Mental Illness, 1996.

<sup>iii</sup> EUFAMI Position Paper on Family Carers' Needs – 2013

<sup>iv</sup> University of Leuven

<sup>v</sup> Addressing the needs of carers during early psychosis. European Federation of Associations of Families of People with Mental Illness (EUFAMI), Leuven, Belgium. Author: Kevin Jones, Secretary General, EUFAMI

<sup>vi</sup> Schulze, B. and W. Rossler. "Caregiver burden in mental illness: review of measurement, findings and interventions in 2004-2005." *Curr Opin Psychiatry* 2005;18(6): 684-691.

<sup>vii</sup> Giron, M., A. Fernandez-Yanez, S. Mana-Alvarenga, A. Molina-Habas, A. Nolasco and M. Gomez-Beneyto. "Efficacy and effectiveness of individual family intervention on social and clinical functioning and family burden in severe schizophrenia: a 2-year randomized controlled study." *Psychol Med* 2010;40(1): 73-84.

<sup>viii</sup> Lieberman, J. A., D. Perkins, A. Belger, M. Chakos, F. Jarskog, K. Boteva and J. Gilmore. "The early stages of schizophrenia: speculations on pathogenesis, pathophysiology, and therapeutic approaches." *Biol Psychiatry* 2001;50(11): 884-897.

<sup>ix</sup> MacCourt, P., Family Caregivers Advisory Committee and Mental Health Commission of Canada. 2013.

<sup>x</sup> Leff J et al., A trial of family therapy versus a relatives' group for schizophrenia. Two-year follow-up. *Br J Psychiatry*. 1990;157:571-577.  
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<sup>xi</sup> MacCourt, P., Family Caregivers Advisory Committee and Mental Health Commission of Canada. 2013.

<sup>xii</sup> Gustavsson A et al., CDBE2010 Study Group. Cost of disorders of the brain in Europe 2010. *Eur Neuropsychopharmacol*. 2011;21:718-779.  
[CrossRef Medline Google Scholar](#)

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<sup>xiii</sup>WFMH, 2009. "Caring for the caregiver: Why your mental health matters when you are caring for others", Accessed April 2014, from [http://wfmh.com/wp-content/uploads/2013/11/WFMH\\_GIAS\\_CaringForTheCaregiver.pdf](http://wfmh.com/wp-content/uploads/2013/11/WFMH_GIAS_CaringForTheCaregiver.pdf)

<sup>xiv</sup>Family carer education in mental health by Kevin Jones, EUFAMI. WHO Regional Office for Europe, Empowerment in Mental Health – Working together towards Leadership. A meeting in partnership with the European Commission. Hosted by EUFAMI. 27-28 October 2010, Leuven, Belgium

<sup>xv</sup>Schizophrenia—Time to Commit to Policy Change, Fleischhacker W, et al. Accepted January 16 2014. Figure 1 - Burden on family carers: what is the bigger picture?. Produced with permission from EUFAMI

<sup>xvi</sup>Schizophrenia—Time to Commit to Policy Change, Fleischhacker W, et al. Accepted January 16 2014.

<sup>xvii</sup> MacCourt, P., Family Caregivers Advisory Committee and Mental Health Commission of Canada. 2013.

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