



## **FAMILY CARERS OF PEOPLE WITH SCHIZOPHRENIA ARE A HIDDEN WORKFORCE AT BREAKING POINT**

*First of its kind international survey highlights the impact on those caring for people with schizophrenia on World Mental Health Day 2014*

**10 October 2014, Leuven, Belgium**—Approximately three out of four (72%) carers of those living with schizophrenia, are mainly [34%] or solely [38%] responsible for caring, placing a huge emotional and physical burden on them, according to the preliminary results of a major international survey revealed on World Mental Health Day (#WMHD14) today. The Caring for Carers [C4C] survey, which is on-going in 25 countries, is being undertaken by the European Federation of Associations of Families of People with Mental Illness [EUFAMI] in collaboration with LUCAS, the interdisciplinary centre for care research and consultancy of the University of Leuven, Belgium.

The first results revealed today are based on responses from more than 400 carers in Australia, Canada, France, Germany, Italy, Spain and UK. It provides evidence of the immense and unspoken burden on people caring for those living with schizophrenia and highlights the contribution they make, and the overwhelming impact this has on their own lives.

Family carers perform their caregiver role for an average of 16 years, are likely to have to do so for the rest of their lives, and report an average of 23 hours a week caring for a loved one, due to the undetermined and long-term nature of schizophrenia. This amount of care equates to a part time job.

In the EU, there are approximately 10 million family carers caring and supporting their child or sibling with a serious mental health condition on a daily basis. This is a massive and valuable contribution, not just to individuals, but to society as whole and to the financially strained healthcare systems across Europe. "This hidden workforce of family carers is a lifeline for society and we must take steps to ensure they are fully recognised for their contributions, their voices are heard and they are supported in order to allow them to continue caring effectively and safely for their loved ones, without putting their own physical and emotional well-being at risk," Kevin Jones, Secretary General, EUFAMI, said today.

Although about one third of the carers report positive experiences of providing care, the survey also indicates that almost 4 out of 10 battle with feelings of being unable to cope with the 'constant anxiety' of caring and one third feel depressed. More than 1 in 10 carers worry about feeling isolated and experience strains in their social network because of the care they give.

The average age of the carers surveyed was 61 years old, with the majority [84%] caring for a son or daughter. Many express deep concerns about what will happen to their child when they are unable to care for them or are no longer 'around'.

With this constant level of pressure, a third of carers are reported to be reaching '*breaking point*' and feeling they cannot carry on with things the way they are.

The findings emphasise the urgent need for action from both Governments and society to recognise the role of carers, their contribution and the need to provide support and hope for their future.

Positive caregiving experiences are eclipsed by the fact that there is a degree of dissatisfaction with the level of, or lack of, support from care professionals. Ninety two percent of carers surveyed want more support on several domains.

The survey highlights carers' desire to be more involved in treatment conversations and to be better equipped to influence care decisions.

"There is a lack of support and dissatisfaction being expressed by family carers. Thirty eight per cent feel they are not taken seriously by medical/care staff and 44% are not feeling satisfied with their ability to influence important decisions in treatment and care planning," said Kevin Jones, Secretary General, EUFAMI. "Healthcare professionals need to acknowledge that family carers can play a much stronger role, integrate them in treatment decisions and work together to achieve better outcomes for the patient. EUFAMI has been calling for this approach for many years."

"In addition, several caregivers experience a financial burden due to their caregiving," said Prof. Dr. Chantal Van Audenhove, director of LUCAS. "They become trapped in a so-called sandwich situation: the obligations towards their family member and towards their own job are in conflict. When there is not enough understanding on the part of the employer, some people even lose their job, which in return is also a loss of talent for society. More work flexibility should be on the policy agenda."

Schizophrenia is a disabling mental illness that impacts lives, both of the people living with it, and those who care for them, and touches approximately 24 million people worldwide. It affects mainly people aged 15–35<sup>1</sup> and is ranked among the top10 leading causes of years lost to disability<sup>2</sup>. Family members are the likely primary carers of people living with schizophrenia, and can spend an average of 6-9 hours a day caring, and consequently experience high personal impact which can threaten their own long-term well-being. Severe mental disorders like schizophrenia cost €93.9 billion a year in Europe alone, making it one of the most expensive diseases to treat<sup>3</sup>.

The survey, supported by an educational grant from major CNS alliance, Lundbeck and Otsuka, has been developed by EUFAMI in collaboration with the University of Leuven according to robust methodology and analysed by its interdisciplinary research centre LUCAS, led by Prof. Dr. Chantal Van Audenhove, Director of LUCAS. The survey, once complete, will gather insights from a total of 25 countries, mainly European, and the results will be published in 2015.

You can follow the conversation around the C4C Survey and World Mental Health Day on EUFAMI'S Facebook page <https://www.facebook.com/pages/EUFAMI/127281550633653> and on Twitter using the hashtags #WMHD14 and #LivingWithSchizophrenia.

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***Notes to Editors:***

- The survey is focusing on members of families of people with severe mental illness (included are carers who take on acute care as well as long term care), with around 90% of respondents caring for someone with schizophrenia.
- For more details about the survey, EUFAMI and University of Leuven please see accompanying factsheets and infographics.
- The survey was developed and analysed by EUFAMI and a team at the interdisciplinary research centre LUCAS, of a leading academic institute, the University of Leuven, in Belgium.

**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).

### **About World Mental Health Day**

The World Mental Health Day (WMHD) initiative is driven by the World Federation for Mental Health (WFMH) and is an annual campaign. This year the theme is 'Living with Schizophrenia'.

### **REFERENCES:**

<sup>1</sup>WHO, 2011

<sup>2</sup>WHO, 2004

<sup>3</sup>Cost of disorders of the brain in Europe 2010, Jes Olesen et al. (2011)

### **MEDIA CONTACT**

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