



JOINT ACTION MENTAL HEALTH AND WELLBEING FINAL CONFERENCE

21-22 JANUARY 2016

BRUSSELS

EUFAMI *Survey on the Experiences of Family Caregivers
for People with Severe Mental Illness*

Bert Johnson
President EUFAMI



EUFAMI

**European Federation of Associations of Families of People with Mental Illness
Europese Federatie van Verenigingen van Familieleden van de Psychisch Zieken
Fédération européenne des Associations de Familles de Malades Psychiques
Europäische Föderation von Organisationen der Angehörigen psychisch Kranker**

**Founded in 1992 – 20 years
anniversary – 19th December 2012**

**Represents circa 25 million families
in Europe**

**34 member organisations in 24
countries**

**EUFAMI's mission is to represent all
family members of persons affected
by severe mental illness at
European level so that their rights
and interests are protected and
promoted**





The Fundamental Policy Driver

-
- **Worldwide shift in mental health policies away from hospital-based to community-based care**
 - **Makes the role of families in caring for people with severe mental illness ever more essential**
 - **Creates increasing demands with a huge impact on caregivers' own lives**
 - **So only half a policy: other half would be a comprehensive strategy to provide fully for community based care with due weight and resources given to family carers**



The EUFAMI Survey: Caring for Carers C4C - An International Perspective

- Over 1000 responses from 22 countries
- 64% related to schizophrenia

Explores

- The experiences of family caregivers including their own health and well being
- Their satisfaction with the professional support they receive
- Their needs for further support



Key Findings: Experience

-
- **The harsh realities of living with mental illness**
 - **Feelings of isolation, loneliness and intolerable stress, emotional and financial**
 - **Accumulation of unsought burden on several areas of life**
 - **4 in 10 feel unable to cope with constant anxiety**
 - **But not all doom and gloom – these can be coupled with positive care giving experiences**
-



Key Findings: Satisfaction

- **Varying degrees of dissatisfaction with support received from doctors, nurses and social workers, and in the workplace**
 - **Specifically, with lack of information on who to contact in case of emergency and on the longer term prospects for their family member**
 - **Also lack of involvement in important decisions**
 - **Most satisfaction (6 in 10) with support from patient and caregiver organisations**
-



Key Findings: Further Needs (1)

- **93% would appreciate additional support in their role as a caregiver: half of them wanting a significant amount**
- **Further essential information is critical**
- **9 in 10 want more opportunities to meet and share experiences with both professional and other informal family carers**



Conclusions

- **The care of people with mental illness is a huge issue with profound implications for the well being of millions and for our social and economic future. All civil society should be involved**

THE GREATEST NEED OF FAMILY CAREGIVERS LIES IN THE RECOGNITION THAT THEY ARE A FULL PARTNER IN CARE, TO BE LISTENED TO AND TAKEN SERIOUSLY BY PROFESSIONAL CAREGIVERS.



Recommendations (1)

For professional caregivers and organisations:

- **Educate them to pay attention to family caregivers in their different roles**
- **Train them to listen to the individual needs of family caregivers and tune into the specific burdens confronting them**



Recommendations (2)

For the general public and family caregivers:

- **Educate people about mental health and the care this requires**
- **Empower families to recognise their own care giving limits and capacities, their burdens and strengths**
- **Sensitise employers to support chronic family care giving**



Recommendations (3)

For policy makers:

- **Raise public awareness of the impact of severe mental illness of families to decrease stigma**
- **Stimulate them to incorporate family caregiver interventions into national mental healthcare plans**
- **Encourage and support research to stimulate innovations and to evaluate the effectiveness for family caregivers**
- **Install a diversity of respite opportunities through sharing care giving responsibilities or financing professional respite care**



Thank you for your attention